#### arthritis.org







#### BE A CHAMPION FOR PEOPLE WITH ARTHRITIS

Your Guide to Grassroots Advocacy

Arthritis Advocacy Toolkit



## **Table of Contents**

Introduction	3
Advocacy 101	
Engage	
Federal	37
State	. 51
Conclusion	67
Glossary	. 71

FOR MORE INFORMATION,
CONTACT ADVOCACY@ARTHRITIS.ORG.

BECOME AN ADVOCATE AT WWW.ARTHRITIS.ORG/ADVOCACY.



"The high cost of treatment, difficulty obtaining needed medications, a scarcity of specialists and many more issues can stand in the way of people with arthritis accessing the health care they need. The Arthritis Foundation is THE organization that is committed to addressing key issues on both the state and federal levels with lawmakers, insurers and regulators on behalf of the more than 50 million people, including almost 300,000 children, who deal with arthritis every day. I want to thank our committed network of Advocates and Ambassadors who make this possible."

# Introduction

Our goal is to make sure that all people with arthritis have access to optimal care and game-changing medicine, while making each day another stride towards a cure.



The Arthritis Foundation is the largest and most trusted nonprofit organization dedicated to addressing the needs and challenges of those living with arthritis, the nation's leading cause of disability. Since 1948, the Foundation has remained committed to leading groundbreaking research for better treatments and a cure; fighting for patients' access to affordable and effective health care; and providing trusted information and resources to the more than 50 million adults and approximately 300,000 children living with the disease.

## The Arthritis Foundation Is Leading the Way

#### ACCESS AND ADVOCACY | On Capitol Hill and Beyond

People with arthritis face unique barriers to care: high costs of treatment, difficulty accessing medications, scarcity of specialists and coinsurance that limits access to treatment. It's hard for any individual to fight the battle alone. But through the Arthritis Foundation's nationwide network of committed Advocates, we're fighting to address key policy issues on both the state and federal levels with lawmakers, insurers, employers and regulators.

#### SCIENTIFIC DISCOVERY | For Better Treatments and a Cure

The Arthritis Foundation continues to lead and fund cutting-edge scientific investigation to discover more about arthritis – what causes it, what affects it, what can stop it – and what can keep it from developing in the first place. Our new scientific strategy will lead to a faster cure by strengthening the research pipeline and engaging creative minds.

#### HELP AND SUPPORT | When and Where You Need It

At the Arthritis Foundation, we're expanding our reach to assist even more people with arthritis. We offer trusted information, powerful health tracking tools and ways to connect with others. We are working with health care providers and other partners to strengthen our educational and interactive offerings. We're also building a state-of-the-art digital enterprise so you can customize your online experience, find local resources and live better than ever.

#### JUVENILE ARTHRITIS | Our Unwavering Promise to Families

The needs of families living with juvenile arthritis (JA) are unique and urgent. In the United States, an estimated 300,000 children have JA. Multiply that by their parents, siblings, extended family and others, and the number of lives affected is staggering. For almost seven decades, the Arthritis Foundation has upheld our unwavering promise to assist them and their caregivers. We're boldly leading the JA fight, supporting easy access to life-changing resources, community and care.

#### COMMUNITY AND CONNECTIONS | Making a Difference

When you join the movement, you become part of the answer. Our social media communities and fundraising events allow you to form meaningful community connections and find ways to give back – getting the support you need while supporting others.

#### What You Can Do

#### **PARTICIPATE**

Register and raise funds for your nearest annual Walk to Cure Arthritis or Jingle Bell Run/Walk event.

#### **ADVOCATE**

Sign up to be an Arthritis Foundation Advocate and let your voice be heard.

#### **VOLUNTEER**

Find your closest Arthritis Foundation office and get involved.

#### JOIN

Get numerous benefits by becoming a member of the Arthritis Foundation, including a one-year subscription to our award-winning *Arthritis Today* magazine and our annual *Drug Guide*.

#### **DONATE**

For every dollar donated to the Arthritis Foundation, at least 75 cents goes to fund arthritis research and interventions. The Arthritis Foundation meets the strict qualifications of the Better Business Bureau's Wise Giving Alliance, ensuring that your tax-deductible gift is spent in ways that make the greatest difference in the lives of people with arthritis.

## Arthritis Advocacy Toolkit Audience And Purpose

The Arthritis Foundation wants to work with you because you are our most valuable resource. Your voice is crucial – and we can help you amplify it among policymakers.

By telling your story about living with arthritis, you can help ensure that elected officials make treatments accessible and that government funding is increased for arthritis research.

We created the Arthritis Advocacy Toolkit for a broad audience. It's a great resource for individuals interested in advocating for arthritis research and policy issues. This toolkit will educate, engage and empower you to make your voice heard by elected officials and decision makers. Use it to arm yourself with important information that can make a huge difference.

"As the father of a young man with juvenile arthritis and chair of the Arthritis Foundation board, I understand the profound impact of scientific advances for people with arthritis and what a pivotal role the Arthritis Foundation has played in this arena. In order to to continue advancing treatments and pushing for a cure by funding scientific discovery, our efforts in advocacy are crucial. Our Advocates and Ambassadors are on the frontlines day in and day out, meeting and interacting with state and federal legislators, making sure they understand the high cost of arthritis on the economy and on individual lives."

# Advocacy 101

Advocacy is often thought of as intimidating, inaccessible and complicated. This toolkit will show you that it's easier than you may think, and that elected officials want to hear from their constituents on issues.



Whether you are visiting Washington, DC, during the Arthritis Foundation's annual Advocacy Summit or meeting with your state officials, advocating for arthritis issues throughout the country is essential in making medications more affordable, funding new research and ultimately finding a cure.

## Types of Advocacy

#### **PERSONAL**

Represent and speak up for yourself and/or your loved ones. Be informed about the issues and help make sure that necessary changes are made so you can live a healthy, productive life.

#### **COMMUNITY**

Represent the rights and interests of your community, which can be your neighborhood, place of worship, community organization or another group. Work together to build the strongest community possible. A great way to get your community involved is by asking them to sign up to be an Advocate at arthritis.org/advocacy or participate in a local Walk to Cure Arthritis or Jingle Bell Run/Walk event.

#### **MEDIA**

Increase public awareness and influence public interest in arthritis issues through letters to the editor, social media, interviews and other communications opportunities.

#### **LEGISLATIVE**

Reach out to elected officials at the local, state or federal level, educating and influencing them on important legislative decisions. Every individual has a constitutional right to have his or her voice heard by elected decision makers.

#### **POLICY**

Influence laws, regulations and rules that have an impact on your well-being. This can be as lofty as a federal regulation or as simple as a rule at your workplace.



## **Beginning Advocacy**

You have an important story to tell, and you'll need to figure out how to frame your story to have the biggest impact possible. With your compelling personal story, you have the power to help shape public policy.

You may have heard of "grassroots advocacy," which simply means that you, as a constituent, make your voice heard by contacting your elected officials and communicating your position on an issue or piece of legislation. You live in the geographic location your elected officials are obligated to represent. They need to understand your experiences and concerns, and work with you to try to address them.

Do you know others who might also be passionate about arthritis issues? What about...

Friends
Neighbors
Work colleagues
Members of your place of worship
Parents and teachers at your child's school
Professors and students at the local university particularly in fields like public health, social work, public policy, etc.)
Health care professionals
Members of the media
them to be allies in your advocacy efforts.
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U AND ADVOCACY y should you Advocate? What does Arthritis Foundation advocacy mean for you? Are you or a loved one affected by arthritis?

NOW THAT YOU'VE DECIDED TO TAKE A STAND, YOU HAVE TO DECIDE WHAT TO DO NEXT AND WHO YOU NEED TO ENGAGE.

Is your issue legislative or policy-focused? If so, will you address it at the federal, state or local level?

#### **FEDERAL**

If you want to address your concerns at the federal level, you should contact your representative in the U.S. Congress and your two U.S. senators. You can also reach out to the president of the United States, who heads the executive branch of the federal government.

#### **STATE**

If you want to address your concerns at the state level, you should contact your state legislators. Every state (except Nebraska) has a bicameral legislature with both a House and a Senate. The governor of each state heads the executive branch.

#### LOCAL

You can even identify your local elected officials if you want to address a concern at the community or county level.

#### **Set Goals and Tactics**

Advocacy can be challenging. It's difficult to pass bills into law. It helps to form a group of like-minded individuals and work together to advance your cause. Remember: Without your voice, elected officials have no way of knowing about life's daily challenges for people with arthritis.

Once you know the focus of your advocacy campaign, outline your goals and list the steps you need to take to be successful.

#### **EXAMPLE**

A full advocacy plan could include dozens of steps. Policy changes and enacting new laws take time, so be patient. This abbreviated example will give you an idea of how to begin.

Issue: Increase access to affordable medications.

Goal: Work to pass legislation in my state that will increase access to medications by limiting co-pays.

#### Tactics:

- ✓ Reach out to state-based patient advocacy and select provider groups, like the state rheumatology organization that focuses on chronic diseases. Volunteer to work with them on the issue.
- ✔ Determine which members of the state legislature care about access to medications and form relationships.
- ✓ Find pieces of comparable legislation that were enacted in other states, and meet with members of the legislature who may be interested in introducing a similar bill.
- ✓ Research arthritis statistics specific to your state, including how many people have arthritis (children and adults), as well as how much money it costs the state per year.
- ✓ Reach out to the media to cover the issue of access to care for people with arthritis and other chronic diseases.
  Tell your personal story and try to place at least two articles regarding your issue in the press.

✓ Work with local stakeholders, including members of the legislature and nonprofit organizations, to hold a briefing at the state legislature on your issue.

#### Do Your Homework

Do your homework before contacting your elected officials and meeting with them or their staff in person.

Here are some ideas to get you started:

- O Who are your elected officials?
- O What political party do they belong to? Are they Republicans, Democrats or Independents? Are they conservative or liberal?
- O What committees do they sit on? Are these committees relevant to the issue you are addressing?
- O How do they tend to vote or lean on such issues? For instance, are they typically supportive of access to health care issues? Have they been known to vote for increased access to care and cost limits? You can find this information by visiting websites like votesmart.org or by visiting the elected official's website.
- O What issues are most important to your elected officials? Is there any way you can connect your issue to other areas of interest to them? For instance, arthritis may not be their top priority, but perhaps they've shown leadership on diabetes or other chronic diseases with similar policy challenges. Many of the same issues are impacting all people with chronic diseases, so you can use that to your advantage.
- How does your issue affect people who your elected officials represent? Do you have statistics on how many people have arthritis in your community? The Arthritis Foundation advocacy Web page provides important information about the cost of arthritis and the incidence of disability. Many policymakers don't know that kids get arthritis or that people can go blind from arthritis. You may also be able to find state-specific information on your state's department of health website.

#### **Prepare Your Position**

You will need to prepare to discuss an issue with your elected officials, who will want to have as much information as possible in order to make an informed decision about your request. Here are some questions to consider before meeting with elected officials or decision makers:

- O What issue(s) do you care about and want your elected officials to address?
- O Why do you care about the issue(s)? Do you have a personal connection or story?
- O Why should your elected officials care about this issue? How does it affect the health and well-being of their constituents?
- O Is there data to back up your issue (particularly for your district/state)?
- O How does this issue affect your district/state/community?
- O Is there legislation at the state or federal level addressing this issue? If so, which elected official introduced it and who have signed on as co-sponsors?
- Are there other Advocates or organizations that support or oppose this issue? If so, why?
- What is your "ask?" Do you want your elected officials to support or oppose a piece of legislation, provide additional funding for a cause, or stay informed about a certain issue as they make decisions moving forward?
- Will it cost money? If so, how much, and where will that money come from?

#### **Develop a Solution**

It's helpful to approach elected officials with some idea of how they can address the issue you care about, although you're not expected to have all the answers. There may be legislation that has already been introduced, or your elected officials, their staff or other experts may be able to help find a solution.

Putting as many pieces of the puzzle together yourself before approaching your elected officials increases your chance of success.

#### **Take Action**

Now that you've put in all the hard work of preparing, it's time to take action. Elected officials often look to constituents to educate them about specific issues they're not familiar with. Whether you call, email, write a letter or meet with your elected official (or their staff) in person, remember that you want to inform them about your issue and try to persuade them to agree with you.

Later in this kit, you'll find advocacy tools to help you reach out to your elected officials and have the greatest impact possible. Arthritis Foundation staff are always available to assist you by emailing advocacy@arthritis.org.

#### Don't Give Up

There may be obstacles along the way – but don't give up! Advocacy work can move slowly, but the Advocacy and Access team can provide support if you need it.

#### **Evaluate and Report Back**

We want to help you be the best Advocate possible. We'll work with you in making preparations to take action. We also want to hear your feedback once you've done so. Use the reporting form (pg. 29) in this toolkit so we can work together to support your efforts.

## **How Will You Advocate?**

The following activities are examples of different ways in which you can be an advocate.

All of these efforts are personal, because you are taking the initiative to improve your own wellness and create healthier communities. Many of these strategies incorporate other types of advocacy and overlap with one another as you will see below.

	Personal	Community	Media	Legislative	Policy
Ask about your family history	<b>V</b>				
Organize a neighborhood walking group	<b>V</b>	<b>V</b>			
Write a letter to the editor	<b>V</b>		<b>V</b>		
Contact your elected officials in support of legislation	<b>✓</b>			<b>V</b>	
Encourage your employer to provide a wellness policy	<b>/</b>				<b>/</b>
Maintain a healthy weight and eat a healthy diet	<b>/</b>				
Encourage family, friends and neighbors to take care of themselves	<b>/</b>	<b>/</b>			
Write an op-ed piece	<b>V</b>		<b>V</b>		
Stay up to date on arthritis-related legislation at state and federal levels	<b>~</b>			~	
Understand how the Affordable Care Act (ACA) impacts you and your family	<b>/</b>				~
Work with your local government agency to develop hiking and bike trails	<b>/</b>	<b>/</b>			<b>/</b>
Stay up to date on news stories and utilize social media to educate others	<b>/</b>	<b>/</b>	<b>/</b>		

"Advocacy is a core part of the **Arthritis Foundation's efforts to** help people with arthritis live the lives they envision for themselves. Building a comprehensive and effective advocacy program means not only working with state and federal legislators, but also expanding our work with employers and insurance payers and providers who are a critical part of this conversation. The Arthritis Foundation is in a unique position to lead the fight for optimal care on behalf of people with arthritis and to help ease their health care burdens so they can reach their goals."

# Engage

Engaging in advocacy doesn't have to be difficult.



## **Publication Letters**

Elected officials want to hear from you, and the tips, scripts and sample letters in this section can help you effectively communicate with them and achieve your goals.

#### Letters to the Editor vs. Op-Eds

A letter to the editor is similar to an op-ed; however, the two formats are used for different reasons. A letter to the editor is a short letter in response to a story in the news or to an editorial. Op-eds are a longer opinion piece, usually written on broader issues. A typical letter to the editor is about 200 words long, or two paragraphs. An op-ed can be as long as 800 words, or five paragraphs.

## Differences Between an Op-ed and a Letter to the Editor

	Op-Ed	Letter to the Editor
Торіс	Usually written about an issue of interest to the writer	Written in response to an article, op-ed or editorial
Purpose	To highlight an issue	To respond to an issue
Length	500+ words or five paragraphs; similar to an essay	150-300 words or two paragraphs; similar to an email response
Author	Anyone who has knowledge on a topic	Anyone who has interest in a topic

#### 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. This sample letter and tips can help you in drafting your own letter to the editor.

#### **Writing Tips**

Check the publication's website for guidelines on letters to the editor to make sure your piece satisfies length and formatting requirements. Be sure to send it to the specific contact listed for this purpose. This may be an online form or email address.

**KEEP IT CONCISE.** Each media outlet has a maximum word count. Focus on just one major concept or idea and limit it to 200 to 250 words.

**OPEN WITH** the title of the article or editorial you are responding to and when that piece was published.

**DON'T MAKE IT COMPLICATED.** Remember, not everyone will have read the piece you are referencing or be familiar with your topic. Keep your writing simple and avoid acronyms and jargon.

**KEEP IT RELEVANT.** Write about an event in the news or piece that was recently published and cite the article.

**MAKE IT RELATABLE.** Write about something that pertains to your community. Explain how your topic impacts your community and, if possible, include an example from your personal experience.

**BEGIN YOUR LETTER BY STATING YOUR THOUGHTS** on an article, editorial or recent event. You can express disagreement, contribute to the discussion by offering information, or point out inaccuracies in an article.

**END YOUR LETTER BY STATING THE MAIN POINT** you would like your audience to take away from your letter. Include your name, address and phone number, as well as any relevant academic degrees to demonstrate your qualifications to the media. And, if you are writing on behalf of an organization, be sure to include the name of that organization in your letter.

**DON'T MAKE PERSONAL ATTACKS.** Avoid emphasizing that a reporter, editor, expert or other individual was wrong.

**WRITE AND SUBMIT YOUR LETTER AS QUICKLY AS POSSIBLE** so that it's still relevant. If it has been more than a week after the original article or column appeared, it is too late.

**HAVE SOMEONE REVIEW YOUR WRITING** to make sure it is clear and effective. If your letter is published and if it is relevant, send a copy to your elected official's office.



## **Example Letter to the Editor**

July 8, 2015

To Whom it May Concern,

I am writing this letter in response to the editorial published on February 10, "The Cost of Health." I was diagnosed with rheumatoid arthritis (RA) when I was 34; I am now 51. I worked as an electrician for many years until my arthritis forced me to retire early from the job I loved. I take three pills every day and a biologic once a week to live a normal life. Thankfully, I have insurance under my wife's employer-sponsored plan. Even with our insurance plan, my medication costs over \$900 per month. For a person on a limited income, this amount is outrageous.

Capping the co-pay would go a long way to making sure I can afford my medicines and that I don¹t miss any doses. Even one missed dose can make my RA flare, and that is obviously something I don't want to go through. I applaud Sen. Jane Smith's efforts to limit the cost of medicine and cap the co pay. Limiting the cost of a 30-day supply of each of my medicines to \$150, as Sen. Smith has supported, would save over \$300 per month. I urge all of our state lawmakers to join Sen. Smith in her efforts to limit high health care costs.

Sincerely,

John Jones

Atlanta, GA

### 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. Like a letter to the editor, anyone can submit an op-ed. Doing so allows you to inform the public about relevant issues and shape public opinion. This document provides a list of suggestions to keep in mind as you write your op-ed.

An op-ed is similar to a letter to the editor; however, there are some differences. People typically write a letter to the editor in response to an editorial or an article. Op-eds are often about broader issues. Letters to the editor are also much shorter (200-250 words) than op-eds (500-800 words).

#### **Writing Tips**

**CHECK THE PUBLICATION'S WEBSITE FOR GUIDELINES** on op-eds to make sure your piece satisfies the length and formatting requirements. This information is usually located under the opinion section on the publication's website.

**INCLUDE YOUR NAME, ADDRESS AND PHONE NUMBER** so the publication can confirm your identity. Include what makes you an expert on the topic. If you have any relevant academic degrees, include those as well so the media is aware of your qualifications.

**KEEP IT CONCISE.** Focus on one or two major concepts or ideas and limit it to 500-800 words.

**DON'T MAKE IT COMPLICATED.** Remember, not everyone will have a thorough understanding of your topic. Keep your writing simple and avoid acronyms and jargon.

**INCLUDE PERSONAL ANECDOTES.** This will help engage your audience. Keep it relevant. Choose a topic that relates to current events.

#### **DON'T MAKE PERSONAL ATTACKS.**

**MAKE SPECIFIC CALLS FOR ACTION.** Conclude your piece by suggesting that your readers call their elected officials or suggesting that elected officials vote "yes" or "no" on a specific piece of legislation or policy.

**HAVE SOMEONE REVIEW YOUR WRITING** to make sure it is clear and effective.



## The Idaho Board of Pharmacy is about to disrupt the relationship between patients and doctors

By Susan Rogers

The Idaho Board of Pharmacy is considering a proposed rule to allow pharmacists to unilaterally substitute complex specialty medications, known as biologics, with biosimilar drugs – without providing any notice or communication to the doctor.

As the mother of a child with doctor-diagnosed juvenile arthritis, I am disturbed at the thought of a pharmacist giving my daughter any medication other than that which her doctor has prescribed and without notifying the doctor.

There are more than 1,500 children in Idaho currently living with juvenile arthritis, and the board needs to know that Idaho's parents are not willing to put our children at risk. The failure to alert doctors that a change in medication has been made could disrupt the relationship between patients and doctors, and undermine the doctor's judgment and experience with individual patients.

Biologic medications have been extremely successful at helping people with arthritis and other chronic conditions lead full and productive lives. Unlike most traditional prescription drugs that are made through chemical processes, biological products are generally made from human and/or animal materials.

Entering the marketplace in the near future will be a new class of medications called "biosimilars," which will be therapeutically equivalent to or interchangeable with biologics and are predicted to have a lower cost. People with arthritis need access to a range of innovative medications, such as biosimilars, but not at the risk to patient safety.

Fortunately, there is time for the Idaho Board of Pharmacy to get this issue right and include doctor communication when the board updates its rule on biologic substitution. On behalf of the parents of all children suffering from juvenile arthritis, as well as my own child, I ask the board to include language in their updated rule that ensures that doctor communication is mandatory whenever a biosimilar drug is substituted for a biologic.

Susan Rogers is a health care professional based in Boise, ID, and an Advocate who volunteers with the Arthritis Foundation.

## Calling Elected Officials

There are often times when it's appropriate and important for constituents to contact their elected officials in support of or 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.

#### **BEFORE THE CALL**

It's essential to be prepared when you make such a call. This draft call script should 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 that 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. Please tailor this script to your specific advocacy needs.

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.

#### **DRAFT CALL SCRIPT**

INTRODUCTION		
Speaking to Receptionist:		
Hello. My name is	and I am a constituent of (Senator/Represen	tative). May I
please speak with the legislati	ve aide who handles issues related to	(health care/arthritis)?
Speaking to Legislative Aide	<b>::</b>	
Hello. My name is	and I am one of (Senator/Representative	)'s constituents. I
am calling today about (bill n	ame/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 iss	sue?
PAUSE FOR FEEDBACK		
Option 1: If the elected of	ficial is in favor of your position O	
Speaking to Legislative Aide	<b>::</b>	
Thank you for that information	on. I'm pleased to hear that (Senator/Representativ	ve) is supportive
of this position. May I give yo	ou my contact information so that I can serve as a	resource on this issue?

#### Speaking to Legislative Aide:

**PAUSE FOR FEEDBACK** 

Thank you for your time and work on this issue.

#### Option 2: If the elected official is in opposition to your position or neutral

#### Speaking to Legislative Aide:

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

#### **PAUSE FOR FEEDBACK**

#### Speaking to Legislative Aide:

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**

#### Speaking to Legislative Aide:

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





The Arthritis Foundation can help put you in touch with the specific staffer you need to speak with about an issue. Contact advocacy@arthritis.org for more information.

- O Make sure you pronounce and spell the staff person's name correctly.
- O Treat staff with respect on the phone and in all written correspondence.
- Keep your call brief. Staff members are very busy and will appreciate you getting your point across clearly and succinctly.
- O Be confident. You know about your issue. Tell a personal story about why you hold your position and why the elected official should consider the position you hold.
- O Do not be defensive and do not attack the elected official or staff member.
- O Have supporting documents and data in front of you when you make your call. This can help with any questions they have.
- 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 get back to them.
- O If you don't understand something, ask for clarification.
- Ask for a specific action from your elected official. Be clear about your request. Never leave a meeting without making a specific ask.
- O Don't be nervous. Legislative staff appreciate hearing from constituents and gathering information to help the elected official make informed decisions.
- O Don't give up. If you don't get in touch with a staffer right away, keep trying.

#### **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 committed to sending additional information regarding your issue, you should include:

- O Your contact information, including full name, address, email and phone number
- O The issue or bill (including name and number) you would like to address
- O Your position on the issue or bill
- Supporting facts
- O Personal story (if applicable)
- The action you would like your elected official to take on the measure (e.g., co-sponsor a bill, vote in favor of or opposition to a bill, move a bill out of committee, take a particular position on an issue)
- A sincere thank you and an offer to serve as a resource
- O Remember: The Arthritis Foundation advocacy team is always available to support you.

#### FIND YOUR ELECTED OFFICIAL

Do you need to find out your elected official's contact information? Visit www.house.gov or www.senate.gov.

## Visiting Elected Officials

#### **Schedule Request Template**

As an Advocate, it's important to establish a relationship with your elected officials and their staff. A great way to do this is to set up a meeting with their office so you can meet face-to-face to discuss issues relevant to arthritis and share your personal story. You do not have to discuss specific legislation (but you can). 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.

When addressing a letter to an elected official, choose from the following:

#### **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

## Requesting a Visit

Each office has a preferred method of communication. Call the office of your elected official first and ask to speak with the scheduler. Often they will ask you to fax your request, but they may prefer an email.

If you are scheduled to meet with a legislative aide, don't be offended. She or he is the issue expert and has great influence with the elected official. You may have scheduled a meeting with the elected official, and they may not be able to make it due to last-minute scheduling conflicts.

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. 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 Outline
O State your name and where you live
O State the purpose of your call: scheduling a meeting with the elected official and/or their relevant staff
O Keep it short and sweet (under five minutes)
O The issue
O Why you care
O Who will attend the meeting
O Tell the scheduler how you can be reached (via email and/or phone)
Email/Fax
Ct. t

- O State your name and address
- O State the purpose of your letter: scheduling a meeting with the elected official and/or their relevant staff
- O Keep it succinct, but you can briefly go into the issue
- O Why you care (background and supporting information)
- O Who will attend the meeting
- O Close with how you can be reached (via email and/or phone)



## Example Letter to Request a Visit

July 8, 2015

The Honorable Sam Smith United States Senate 100 Hart Senate Office Building Washington, DC 20515

Dear Senator Smith,

My name is \_\_\_\_\_ and I am an Arthritis Foundation advocate and constituent of (Senator/

Representative \_\_\_\_\_\_). I would like to schedule an appointment to discuss (issue/bill).

[Insert additional information that would be helpful for the elected official and/or staff

person to know, such as why this issue is important to you.]

I appreciate your consideration of this request. I can be reached at (email address and phone number).

Sincerely,

John Jones Mailing Address

City, State, ZIP

Hones

DON'T FORGET TO INCLUDE YOUR MAILING ADDRESS. IT'S IMPORTANT FOR YOUR ELECTED OFFICIAL TO KNOW WHERE YOU LIVE.



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

#### **Before The Meeting**

**CONTACT THE SCHEDULER** at 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** what you will discuss with your elected official.

Create clear, easy to understand **TALKING POINTS** for yourself.

**ADDRESS ONLY TWO ISSUES IN ONE MEETING.** Don't overload the elected official or staffer with numerous concerns.

Put together a **PACKET** of information for your elected official (or several if you will meet with a few staffers). This packet should include relevant documents such as:

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

**KNOW YOUR ELECTED OFFICIAL'S LEGISLATIVE BACKGROUND**, including his or her committee assignments and voting record. Politely ask about your legislator's position on the issue you are discussing and why he or she holds that view.

**DO NOT DISREGARD** elected officials who have a different position than yours. By meeting with them, it's possible to soften or even change their views. Be open-minded and polite when responding to counter arguments.

#### **During The Meeting**

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

**EXPECT YOUR MEETING TO BE BRIEF.** They typically last between 15 to 20 minutes. You may also be asked to meet in an unusual place like a hallway or in cramped quarters. Try not to get distracted.

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

**MAKE A BRIEF INTRODUCTION** of everyone in attendance, as well as mentioning where they live. Explain your issue and highlight the top three points you'd like to get across.

**BE CLEAR ABOUT YOUR POSITION** on an issue, even if it differs from your elected official's view.

**INCLUDE PERSONAL ANECDOTES, SPECIFIC EXAMPLES AND DATA** in your meeting 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. It's meaningful to appeal to them through your personal story, but data and facts are incredibly important as well.

**BE CALM AND RESPECTFUL.** Do not use harsh or aggressive language or make personal attacks. Do not argue.

**BE IN CONTROL OF THE MEETING.** During your conversation, if the legislator or staff member goes off topic, bring the discussion back to your issue.

**BE CLEAR AND CONCISE.** Get straight to the point in what you say and only focus on one or two issues. Always tell the truth. Don't exaggerate or make up statistics or stories. Your credibility is the most important tool you have.

#### DON'T COMMIT TO SOMETHING YOU CAN'T DELIVER.

**BE SPECIFIC** and request your elected official to take action. For example, "I ask that you vote for H.R. XXXX."

**DON'T EXPECT** your elected official or his or her team to be an expert on your topic.

**TAKE NOTES DURING THE MEETING.** Stay engaged, but make sure you have enough information written down so you can follow up.

**ASK TO TAKE A PICTURE** with the elected official. Photos are great for social media and traditional media for post-meeting outreach.

**THANK THE ELECTED OFFICIAL AND/OR STAFF** for their time meeting with you and for their attention to the issue.

**ADMIT YOU DON'T KNOW** if you are asked a question and don't have the answer. Tell the person who is asking the question that you will find the answer and get back to him or her.

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

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

#### **After The Meeting**

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

**CONTINUE TO FOLLOW THE ISSUE.** If your elected official made a promise and did not keep it, request an explanation. If he or she did follow through, thank them. This allows you to develop and maintain a relationship with your elected official and his or her staff.

**THANK YOUR ELECTED OFFICIAL AND THEIR STAFF** when they've done something you support. Don't contact your elected official or their staff only when you are upset about an issue or need to request something.

## Follow-Up Form

If you meet with a legislator, our Advocacy and Access team would like to hear about your experience. Below is a standard follow-up form to help staff determine the best follow-up and how to direct our efforts.

$\mathbf{O}$	Your name
	Phone number
	Email address_
	Meeting date
	Name of elected official
	Elected official state and district
	Name of staff
	Issues or bill discussed
0	What is the position of the elected official on this issue?
0	Does the elected official hear from other constituents on this issue?
0	Is follow-up needed from Arthritis Foundation staff?
0	Any other notes

## Writing Elected Officials

## Letter Writing Tips

Emails to your elected officials and their staff are important. Whether you have recently had a meeting with them or you are writing about an issue, email is the most efficient way to communicate your message. However, letters often stand out more. People rarely take the time to type or even handwrite a letter, so by following up your email with a letter, your message will be unique.

It may take several weeks for your elected official to receive your letter due to security protocol. Once this time period has passed, call your elected official's office to make sure the letter was received by the aide who handles the issue.

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

**WRITE THE ELECTED OFFICIALS WHO REPRESENT YOU.** The only exception to this is if you want to write a letter to someone in a position of leadership, such as a committee chair, the speaker of the House of Representatives or majority leader.

**BE CLEAR AND CONCISE.** 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.

**BEGIN YOUR LETTER BY INTRODUCING YOURSELF** and including whether you are writing as a constituent or on behalf of an organization (or both).

**STATE YOUR REASON FOR WRITING.** If you are discussing a bill, be sure to include the bill's name and number.

#### **INCLUDE PERSONAL ANECDOTES, SPECIFIC EXAMPLES AND RELEVANT DATA to**

demonstrate the importance of this issue and help your elected official understand why this issue matters and how it specifically affects his/her constituents.

**REQUEST THAT YOUR ELECTED OFFICIAL TAKE ACTION, AND BE SPECIFIC.** 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."

#### AT THE END OF YOUR LETTER, THANK YOUR ELECTED OFFICIAL FOR HIS OR HER TIME

and offer to answer any additional questions they might have or provide further information. Include your contact information and sign the letter.



## ADDRESS YOUR LETTER CORRECTLY. INCLUDE YOUR ADDRESS ON THE EMAIL OR LETTER AND ENVELOPE.

#### 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

## **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:

- O "Like" the Arthritis Foundation and other health and wellness organizations on Facebook. You'll get frequent health and wellness updates on your newsfeed.
- O Share relevant posts on your wall for your friends to see and learn from.
- O 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:**

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

POSSIBLE POSITIVE OUTCOME: THE ARTICLES AND ADVOCACY INFORMATION YOU SHARE MAY ENCOURAGE OTHERS TO BECOME AN ADVOCATE.

### TWITTER (@ArthritisFdn)

Users send out short (140 characters or fewer) messages called tweets. Tweets can be posted on the feed for followers to see, or tweeted directly at individuals, for only them to see.

#### What You Can Do:

- O Follow the Arthritis Foundation and other health and wellness organizations on Twitter.
- O Retweet tweets you like about arthritis and management techniques.
- O Tweet at your elected official an advocacy issue you care about.

#### **Best Practices:**

- O If your tweets begin with a Twitter handle, use a period before the handle if you want all of your followers to see it. Example: .@congressmember please vote for bill outlawing use of tanning beds by minors. Without the period, it will only be sent to your elected official.
- O Less is more. Tweets that don't use all 140 characters get more traction.
- O Make it a conversation. Don't just tweet. Favorite and reply to tweets you find relevant and interesting.
- O If you want to add a thought when retweeting, write "your comment here" RT @twitterhandle "the original tweet."
- O Use hashtags so more people can find your posts. Example: #arthritis #ra
- O Use a link shortener like .bitly to save characters.

POSSIBLE POSITIVE OUTCOME: ENOUGH TWEETS COULD EDUCATE YOUR ELECTED OFFICIAL ABOUT WHAT MATTERS TO HIS/HER CONSTITUENTS.

## YOUTUBE (YouTube.com/ArthritisFDN)

Users upload, view and share videos.

#### What You Can Do:

- O Subscribe to the Arthritis Foundation and other health and wellness organizations on YouTube.
- O Create playlists of health and wellness videos.
- O Upload your own videos sharing healthy recipes, workout tips, etc.
- O Comment on videos you like.

#### **Best Practices:**

- O When uploading videos, use lots of relevant tags so people can find them.
- O Share your playlists on other social networks like Facebook and Twitter.

POSSIBLE POSITIVE OUTCOME: SOMEONE FOUND YOUR EXERCISE PLAYLIST AND HAS A WEEK'S WORTH OF NEW WORKOUTS TO TRY.

## INSTAGRAM (@arthritisfoundation)

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

#### What You Can Do:

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

#### **Best Practices:**

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

POSSIBLE POSITIVE OUTCOME: YOUR HEALTHY SALAD PHOTO COULD INSPIRE MANY TO OPT FOR A HEALTHIER MEAL.



#### ENGAGEMENT THROUGHOUT THE YEAR

There are many options for you to stay involved in advocacy year-round! Below are several events and programs to take action for Arthritis Foundation advocacy:

- 1. Join the Ambassador program. Ambassadors are the Arthritis Foundation's most engaged and elite advocates and serve as a liaison between the Arthritis Foundation and their member of Congress. As an Ambassador, it's your privilege to represent the more than 50 million Americans living with arthritis.
- The Ambassador year runs from October to September.
- Any new Ambassadors must fill out an online application to become an Ambassador. New Ambassadors are required to attend a New Ambassador Orientation.
- Existing Ambassadors must fill out an Ambassador Commitment form. Those who fail to sign the form by the first of February each year will be removed from the program and must reapply.
- Ambassadors must reside in the state and district they advocate in. For instance, an Ambassador cannot live in Chicago and vote in Kansas.
- 2. Attend your local Walk to Cure Arthritis or Jingle Bell Run/Walk event.
- 3. Sign up for a peer review program. The Congressionally Directed Medical Research Program at the Department of Defense is a great way to get involved. Reviewers evaluate arthritis research proposals several times per year.
- 4. Enlist your friends and family to become Advocates.
- 5. Serve on a local Arthritis Foundation Advocacy Committee.

# "Progress in Washington, DC, is increasingly made back home.

State and federal policymakers look for widespread grassroots support from organizations and everyday citizens who care enough to lend their voice and their feet to promoting a legislative agenda.

Advocacy can be challenging and time-consuming, yet so rewarding and empowering – especially when great things are accomplished."

- Sandie Preiss, Vice President of Advocacy and Access, Arthritis Foundation

# Federal

Advocacy at the federal level requires understanding the three branches of government: legislative, executive and judicial.



## Legislative Opportunities

### Arthritis Foundation Federal Legislative Agenda

Arthritis affects more than 50 million adults and children in the United States. It's a chronic, complex disease that often requires a lifetime of tailored treatment to manage. Access to providers and treatment is a necessity for people with arthritis. Scientific research is crucial to better understanding the causes of arthritis, in order to develop the best diagnostics, treatments and ultimately a cure.

Below are some key legislative opportunities for 2015 that the Arthritis Foundation considers core priorities.

### **Access to Treatments**

**PATIENTS' ACCESS TO TREATMENTS ACT.** Many people with arthritis rely on expensive specialty drugs to manage their disease. Even with insurance, they can face cost-sharing responsibilities of 40 percent to 50 percent, which is an enormous financial burden. This federal bill would limit cost sharing in specialty tiers (Tier 4 and above) to the Tier 3 non-preferred drug brand level. This helps protect consumers from exorbitant cost-sharing obligations.

**BIOSIMILAR DRUG OVERSIGHT.** Biosimilar drugs, which are similar but not equivalent to complex biologic drugs, have the potential to increase the treatment options for people with autoimmune forms of arthritis. Biosimilars are expected to lower costs and increase access to treatment. The FDA will be releasing guidance this year on how biosimilars will be licensed, including whether they will be required to have unique names, which could have great implications for patient safety. **Congress should ensure that biosimilar licensing requirements meet the highest level of patient safety.** 

#### **Access to Care**

pediatric rheumatologists, with fewer than 200 practicing pediatric rheumatologists in the country. Eleven states have none. In fact, only one-fourth of patients with juvenile arthritis and other rheumatic childhood diseases have access to pediatric rheumatologists. The Affordable Care Act included a provision authorizing loan repayment services to pediatric subspecialists, including pediatric rheumatologists, to help shore up this serious shortage. The program was never funded and the authorization has expired. Congress should reauthorize and fund this program.

### Research

### DEFENSE DEPARTMENT CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP). One

in four active-duty military personnel and veterans has arthritis, which is a considerably higher rate than the civilian population. Over the last five years, the number of arthritis-related topics in the Peer Reviewed Medical Research Program (PRMRP) within CDMRP has grown from zero to four. Given the high prevalence of arthritis among soldiers, Congress should create a separate line item for arthritis within the CDMRP and fund it at \$20 million to help identify early intervention and prevention methods.

NATIONAL INSTITUTES OF HEALTH (NIH). Arthritis research is spread out over many of the NIH's institutes and centers, and a strong NIH funding level is essential for breakthroughs in arthritis diagnostics and treatments. Congress should fund NIH at a minimum of \$32 billion to sustain and grow the investment in arthritis-related biomedical research.

**21ST CENTURY CURES.** There is a bipartisan effort in the House and Senate to change the way medical research is conducted. Currently, there are more than 7,000 known diseases, and only 500 have cures and treatments. Arthritis is one of the many diseases with no cure, and even the best treatments can have severe side effects. The 21st Century Cures project aims to increase participation in clinical trials and close the gap between the needs of science, regulatory burdens and patient safety requirements. **Congress should ensure that patient access and affordability issues are addressed in the 21st Century Cures legislation.** 

**CDC ARTHRITIS PROGRAM.** This program funds public health research in 12 states, and funds data collection and surveillance on the nationwide prevalence of arthritis. This data is essential for determining research and public health priorities. **Congress should restore its funding to the full \$13 million, and seek funds to expand into more states.** 

**PAIN MANAGEMENT.** Rheumatoid arthritis, osteoarthritis and fibromyalgia are among leading chronic conditions where people must use opioids for pain relief. Efforts are under way on the state and federal levels to deter drug abuse. Reasonable policies should govern the use of pain medications and opioids so that pain can be adequately managed in people with arthritis, and so that people with arthritis maintain access to the drugs they need.

The Arthritis Foundation is committed to working with Congress to improve access to providers and treatments for people with arthritis. We're also committed to strengthening the biomedical research enterprise in our quest to find a cure.

Please contact Sandie Preiss at 202-887-2910 or spreiss@arthritis.org with any questions or for more information.

### Patients' Access to Treatments Act

Prescription medications are developed to help improve and maintain health and quality of life, and to keep people in the workforce, with their families and in their communities. Accessing affordable medications is vital for all Americans, but especially for those with chronic, disabling and sometimes life-threatening conditions, like multiple sclerosis, rheumatoid arthritis, psoriatic arthritis, lupus, cancer, HIV and primary immunodeficiency diseases.

## AN ALARMING TREND IN TODAY'S HEALTH INSURANCE MARKET IS THE PRACTICE OF MOVING MORE EXPENSIVE SO-CALLED SPECIALTY DRUGS INTO SPECIALTY TIERS THAT UTILIZE HIGH PATIENT COST-SHARING METHODS.

- O Specialty tiers commonly require patients to pay a percentage of the cost of the drug (co-insurance) that can range from 25 percent to 50 percent or higher, costing a patient hundreds, even thousands, of dollars per month out-of-pocket for a single medication.
- Specialty tiers and co-insurance are placing medically-necessary treatments out of reach of average insured Americans.
- A patient's financial responsibility or cost sharing for a prescription medication should not be so large that it restricts or interferes with medically-necessary use of medications.
- Failure to adhere to a treatment plan because of lack of access to medications can lead to worsening conditions, increased rates of disability, loss of function, productivity and independence, and rising health care costs as more patients forego treatment.
- O Non-adherence to medication regimens not only has a direct impact on health and disease progression; it also contributes to direct annual costs of \$100 billion to the U.S. health care system. Indirect costs exceed \$1.5 billion annually in lost patient earnings and \$50 billion in lost productivity.

### Take Action and Co-Sponsor PATA

The bipartisan Patients' Access to Treatments Acts, introduced by Reps. David McKinley (R-WV) and Lois Capps (D-CA), proposes to limit cost-sharing requirements applicable to medications in a specialty drug tier (typically Tier 4 or higher) to the dollar amount applicable to drugs in a non-preferred brand drug tier (typically Tier 3).





### **Example Letter to Member of Congress**

January 27, 2015

The Honorable (name)
United States Senate
(Building and Office Number)
Washington, DC 20510

Dear Senator (name),

As an advocate for people living with arthritis and a supporter of the Arthritis Foundation, the largest nonprofit dedicated to supporting people with arthritis, I urge you to co-sponsor the Patients' Access to Treatments Act (PATA), which would limit burdensome patient cost sharing for expensive specialty tier drugs.

Arthritis affects more than 50 million adults and approximately 300,000 children in the United States. Often an extremely painful and debilitating disease, arthritis impacts each individual differently. My [or other individual's] life with arthritis means... [personal story, including type of arthritis, how long, major symptoms, how it affects your life and ability to work/be productive]. [suggest three to four sentences max]

Because of the specialty tier pricing system used by most insurers, consumers must pay anywhere from several hundred to even thousands of dollars a month for helpful arthritis treatments like biologics. Research affirms that the higher the out-of-pocket costs, the less likely patients are to take their medications on time, if at all. This fact is particularly devastating for people with rheumatoid arthritis (RA), as biologics can actually halt the disease's progression.

PATA would alleviate this problem by limiting cost-sharing requirements applicable to medications in a specialty drug tier (typically Tier 4 or higher) to the dollar amount applicable to drugs in a non-preferred brand drug tier (typically Tier 3). Making specialty drugs like biologics more affordable will help ensure that patients have timely access to life-changing drugs and can live more productive lives.

Thank you for your time and attention to this matter. Please consider supporting your constituents with arthritis by co-sponsoring PATA. If you have any questions or if there is additional information I can provide, please do not hesitate to contact me at XXX-XXXX.

Sincerely,

John Jones

Mailing Address, City, State, ZIP

### Arthritis and the Military

### **Background**

One of every four U.S. veterans lives with arthritis, a serious, chronic and complex disease that affects one in five Americans in the general population. Arthritis carries with it enormous physical, financial and societal costs, but for veterans and service members, the costs are multiplied because of the consequences of active duty.

Today, arthritis is the top cause of disability among veterans and one of the major reasons that military personnel are discharged from service. Research supporting better prevention strategies, interventions and treatments is crucial to reducing the number of soldiers and veterans suffering from arthritis.

### What Arthritis Does to Veterans and Soldiers

Osteoarthritis (OA) is the second most common reason soldiers are discharged. A 10-year review of arthritis in active duty military found OA rates to be 26 percent higher in the under-20 age group, compared with the same age group in the general population. Data from the Army's Physical Evaluation Board revealed that arthritis was the most common unfitting condition, with 94.4 percent of cases attributed to combat injury. Traumatic anterior cruciate ligament (ACL) injuries occur frequently among service members, and can lead to the development of arthritis and possible joint reconstruction within 20 years. In fact, over 3,000 ACL reconstructions are performed every year in U.S. military hospitals. Musculoskeletal injuries are pervasive and represent 68 percent of all limited-duty orders, even in non-combat units.

### What Military Personnel With Arthritis Have in Common

One in four veterans has arthritis (25.6 percent), compared to one in five civilians. Individuals over age 40 are twice as likely to develop arthritis after returning to civilian life. Wounded warriors will need costly lifelong care for this progressively degenerative condition. Soldiers injured by roadside bombs and other blasts are often diagnosed with the condition within two years of being injured, versus civilian injuries where onset of arthritis usually occurs 10 years later. Arthritis complicates chronic disease management among veterans. More than half of veterans with heart disease or diabetes also have arthritis. Rheumatoid arthritis (RA) is known to advance the progression of cardiovascular disease; data from the Veterans Affairs Rheumatoid Arthritis registry confirms the mortality rate among veterans with RA is considerably more than double the rate among those without RA.

### Why Soldiers Are More Prone to Arthritis

Even in basic training, soldiers are carrying 60-100+ lb. packs that can injure and weaken their joints, which can lead to arthritis. Combat injuries increase the risk for arthritis: For example, shock waves from bomb blasts can cause early joint damage, which in turn may lead to early onset arthritis. Post-traumatic osteoarthritis can be severely debilitating. Soldiers are often injured at a young age, which translates to more years of joint-related symptoms, activity limitations and risks associated with medical procedures.



### How Further Arthritis Research Can Help

Research can help identify ways to reduce joint injury during military training; it's important to study people after a joint injury rather than just looking at people who have already been diagnosed with osteoarthritis. Research on the genetics and epigenetics of rheumatoid arthritis can help us better understand what causes RA, which can lead to more effective treatments with fewer side effects for all people with arthritis.

### Why Department of Defense (DoD)-Funded Arthritis Research Is Key

There is a growing burden of arthritis among active duty military and veteran populations. Arthritis negatively affects the ability of active duty members to perform their duties and limits the quality of life for veterans. Arthritis is responsible for rising DoD and VA health care costs because of its impact on disease management, joint pain, loss of function and joint replacement surgery. Currently, arthritis and clinical care research on both active duty military and veteran populations is very limited.

Arthritis research has been funded at the DoD since Fiscal Year 2010 in the Peer Reviewed Medical Research Program (PRMRP) within the Congressionally Directed Medical Research Program. Since that time, the number of topics authorized by Congress has increased from one to four, and now includes OA, post-traumatic OA, RA and arthritis overall. Fourteen grants have been funded to date, totaling nearly \$17 million. However, arthritis topics compete against the other 37 topics authorized in the PRMRP, so funding is not guaranteed.

### Recommendation

Congress should authorize the creation of a stand-alone arthritis program within the DoD Congressionally Directed Medical Research Program (CDMRP) – funded at \$20 million – to ensure more dedicated research funding to meet the growing needs of active military personnel and veterans. Arthritis research that helps our military and veteran populations will benefit everyone with arthritis, a debilitating disease that attacks one in five americans in the general population.

### Federal Government

The federal government is comprised of three different branches: legislative, executive and judicial.

### **Legislative Branch**

The legislative branch enacts legislation, confirms or rejects presidential appointments, and has the authority to declare war. This branch is composed of Congress, which includes the U.S. Senate and the U.S. House of Representatives. The Senate includes two elected senators per state (for a total of 100). The Senate term is six years and there is no term limit.

The House includes 435 elected representatives (also known as congressmen or congresswomen). These representatives are divided among the 50 states in proportion to their total population, and each representative serves a two-year term with no term limit. Therefore, every individual is represented by two U.S. senators and one representative (with the exception of Americans residing in U.S. territories or in Washington, DC, who are represented by a delegate – a nonvoting member of the U.S. House of Representatives).

### **Executive Branch**

The executive branch carries out and enforces laws. It includes the president, vice president, cabinet, executive departments, federal agencies and other boards, commissions and committees.

#### **Judicial Branch**

The judicial branch interprets the meaning of laws, applies laws to individual cases and decides if laws violate the Constitution. The Supreme Court is the highest court in the United States. The justices of the Supreme Court are nominated by the president and must be approved by the Senate (with at least 51 votes). Congress decides the number of justices and there are currently nine. Justices are appointed for life.

### Leadership of the Senate and the House

### **U.S. Senate**

Sen. Harry Reid (D-NV) Minority Leader | @SenatorReid

Sen. Richard Durbin (D-IL) Minority Whip | @Senator Durbin

Sen. Harry Reid (D-NV) Democratic Conference Committee Chair | @SenatorReid

Sen. Charles Schumer (D-NY) Democratic Conference Committee Vice Chair and

Policy Committee Chair | @SenSchumer

Sen. Patty Murray (D-WA) Democratic Conference Secretary | @PattyMurray

Sen. Mitch McConnell (R-KY) Majority Leader | @McConnellPress

Sen. John Cornyn (R-TX) Majority Whip | @John Cornyn

Sen. John Thune (R-SD) Republican Conference Chair | @SenJohnThune

Sen. John Barrasso (R-WY) Republican Policy Committee Chair | @SenJohnBarrasso

Sen. Roy Blunt (R-MO) Republican Conference Vice Chair | @RoyBlunt

### **U.S. House Of Representatives**

Rep. John Boehner (R-OH) Speaker | @JohnBoehner | @SpeakerBoehner

Rep. Kevin McCarthy (R-CA) Majority Leader | @GOPLeader

Rep. Steve Scalise (R-LA) Majority Whip | @GOPWhip

Rep. Cathy McMorris Rodgers (R-WA) Republican Conference Chair | @cathymcmorris

Rep. Luke Messer (R-IN) Republican Policy Committee Chair | @RepLukeMesser

Rep. Nancy Pelosi (D-CA) Minority Leader | @NancyPelosi

Rep. Steny Hoyer (D-MD) Minority Whip | @WhipHoyer

Rep. James Clyburn (D-SC) Assistant Democratic Leader | @Clyburn

Rep. Xavier Becerra (D-CA) Democratic Caucus Chairman | @RepBecerra

### **Key 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 writes the legislation that allocates federal funds to the 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.

Chair: Sen. Thad Cochran (R-MS) | @SenThadCochran

Ranking Member: Sen. Barbara Mikulski (D-MD) | @SenatorBarb

### SENATE 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.

Chair: Sen. Roy Blunt (R-MO) | @RoyBlunt

Ranking Member: Sen. Patty Murray (D-WA) | @PattyMurray

#### **SENATE SUBCOMMITTEE ON DEFENSE**

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

Chair: Sen. Thad Cochran (R-MS) | @SenThadCochran

Ranking Member: Sen. Patrick Leahy (D-VT) | @SenatorLeahy

#### **SENATE BUDGET COMMITTEE**

The Senate Budget Committee determines fiscal priorities by creating the federal budget. The 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).

Chair: Sen. Michael Enzi (R-WY) | @SenatorEnzi

Ranking Member: Sen. Bernie Sanders (D-VT)  $\mid$  @SenSanders

### **SENATE COMMITTEE ON FINANCE**

The Finance Committee is concerned with matters related to: taxation and other revenue measures generally, and those relating to the insular possessions; bonded debt of the United States; customs, collection districts and ports of entry and delivery; reciprocal trade agreements; tariff and import quotas, and related matters thereto; the transportation of dutiable goods; deposit of public moneys; general revenue sharing; health programs under the Social Security Act, including Medicare, Medicaid, the

Children's Health Insurance Program (CHIP), Temporary Assistance to Needy Families (TANF), and other health and human services programs financed by a specific tax or trust fund; and national social security.

Chair: Sen. Orrin G. Hatch (R-UT) | @OrrinHatch Ranking Member: Sen. Ron Wyden (D-OR) | @RonWyden

#### SENATE COMMITTEE ON HEALTH, EDUCATION, LABOR AND PENSIONS (HELP)

The Senate HELP Committee is composed of three subcommittees, which have broad jurisdiction over our country's health care, education, employment and retirement policies.

Chair: Sen. Lamar Alexander (R-TN) | @SenAlexander Ranking Member: Sen. Patty Murray (D-WA) | @PattyMurray

#### **HOUSE COMMITTEE ON APPROPRIATIONS**

The House Committee on Appropriations has a role that 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 writes the legislation that allocates federal funds to the 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.

Chair: Rep. Hal Rogers (R-KY) | @RepHalRogers Ranking Member: Rep. Nita Lowey (D-NY) | @NitaLowey

### HOUSE SUBCOMMITTEE ON LABOR, HEALTH, HUMAN SERVICES, EDUCATION AND RELATED SERVICES (LHHS)

This subcommittee has jurisdiction over the Department of Education, Department of Health and Human Services, Department of Labor and related agencies.

Chair: Rep. Tom Cole (R-OK) | @TomColeOK04 Ranking Member: Rep. Rosa DeLauro (D-CT) | @rosadelauro

#### **HOUSE SUBCOMMITTEE ON DEFENSE**

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

Chair: Rep. Rodney Frelinghuysen (R-NY) | @USRepRodney Ranking Member: Rep. Pete Visclosky (D-IN) | @RepVisclosky

### **HOUSE COMMITTEE ON THE BUDGET**

The House Budget Committee determines fiscal priorities by creating the federal budget. The budget committees (including the Senate 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).

 $\label{lem:chair:Rep.TomPrice} Chair: Rep. Tom Price \ (R-MI) \ | \ @RepTomPrice \\ Ranking \ Member: Rep. Chris \ Van Hollen \ (D-MD) \ | \ @Chris \ Van Hollen \\$ 

#### **HOUSE COMMITTEE ON ENERGY AND COMMERCE**

The House Committee on Energy and Commerce is vested with the broadest jurisdiction of any congressional authorizing authority. It has responsibility for the nation's telecommunications, consumer protection, food and drug safety, public health research, environmental quality, energy policy, and interstate and foreign commerce. It also oversees multiple cabinet-level departments and independent agencies, including the Departments of Energy, Health and Human Services, Commerce and Transportation, as well as the Environmental Protection Agency, the Federal Trade Commission, the Food and Drug Administration and the Federal Communications Commission.

Chair: Rep. Fred Upton (R-MI) | @RepFredUpton Ranking Member: Rep. Frank Pallone (D-NJ) | @FrankPallone

#### **HOUSE 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.

Chair: Rep. Joe Pitts (R-PA) | @RepJoePitts Ranking Member: Rep. Gene Green (D-TX) | @RepGeneGreen

#### **HOUSE WAYS AND MEANS COMMITTEE**

The House Ways and Means Committee is the chief tax-writing committee in the House of Representatives. The committee derives a large share of its jurisdiction from the U.S. Constitution, which declares, "All bills for raising revenue shall originate 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.

Chair: Rep. Paul Ryan (R-WI) | @PRyan Ranking Member: Rep. Sander Levin (D-MI) | @repsandylevin

### **Key Departments**

#### **DEPARTMENT OF DEFENSE (DOD)**

The DOD's mission is to provide military forces to protect the security of our country and remain sovereign. The Department of Defense is one of the oldest and largest government agencies is the history of the United States. The DOD's main objective is to keep Americans safe. The main branches under the Department of Defense are the Office of the Secretary of Defense, Department of the Army, Department of the Navy, Department of the Air Force and Joint Chiefs of Staff.

#### **DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)**

The mission of HHS is to help provide the building blocks that Americans need to live healthy, successful lives. HHS fulfills that mission every day by providing millions of children, families and seniors with access to high quality health care, by helping people find jobs and parents find affordable child care, by keeping the food on Americans' shelves safe and infectious diseases at bay, and by pushing the boundaries of how we diagnose and treat disease.

### **Key Agencies**

### **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

The CDC 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, caused by human error or deliberate attack, the CDC fights disease and supports communities and citizens to do the same. The CDC increases the health security of our nation. As our health protection agency, the CDC saves lives and protects people from health threats. To accomplish their mission, the CDC conducts critical science and provides health information that protects our nation against expensive and dangerous health threats, and responds when these arise.

### **CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)**

CMS covers 100 million people through Medicare, Medicaid and the Children's Health Insurance Program, and through the Health Insurance Marketplace. The CMS aims to achieve a high quality health care system, as well as better care at lower costs and improved health.

### **FOOD AND DRUG ADMINISTRATION (FDA)**

The FDA is an agency within the U.S. Department of Health and Human Services that is responsible for protecting public health by assuring the safety, effectiveness, quality and security of human and veterinary drugs, vaccines and other biological products, and medical devices. The FDA is also responsible for the safety and security of most of our nation's food supply, all cosmetics, dietary supplements and products that give off radiation. The FDA also regulates tobacco products and is tasked with advancing public health by helping to speed product innovations.

### **HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)**

HRSA, an agency of HHS, is the primary federal agency for improving access to health care by strengthening the health care workforce, building healthy communities and achieving health equity. HRSA's programs provide health care to people who are geographically isolated, or are economically or medically vulnerable. This includes people living with HIV/AIDS, pregnant women, mothers and their families, and those in need of high quality primary health care. HRSA also supports the training of health professionals, the distribution of providers to areas where they are needed most and improvements in health care delivery. HRSA oversees organ, bone marrow and cord blood donation. It compensates individuals harmed by vaccination, and maintains databases that protect against health care malpractice, waste, fraud and abuse.

### **NATIONAL INSTITUTES OF HEALTH (NIH)**

The National Institutes of Health (NIH), a part of HHS, is the nation's medical research agency – making important discoveries that improve health and save lives. Thanks in large part to NIH-funded medical research, Americans today are living longer and healthier. Life expectancy in the United States has jumped from 47 years in 1900 to 78 years as reported in 2009, and disability in people over age 65 has dropped dramatically in the past three decades.

### **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 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).



### 1

### 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.





# Arthritis Foundation Advocacy and Access Guiding Principles

The Arthritis Foundation will be the authoritative leader and help people with arthritis by:

- Strengthening the patient/provider relationship and ensuring access to safe, affordable and quality care
- Educating, empowering and advocating to legislators, insurance providers, employers, regulators and health care providers on behalf of people with arthritis
- Advocating for funding for public health and scientific arthritis related research

## State

Much like the federal government, advocacy at the state level requires understanding the three branches of government: legislative, executive and judicial.



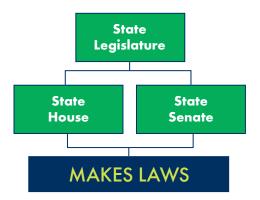
### **STATE GOVERNMENT**

State governments are comprised of three different branches: legislative, executive and judicial.

### **Legislative Branch**

In general, state legislative branches enact legislation. Every state (except Nebraska) has a bicameral legislature with both a House and a Senate.

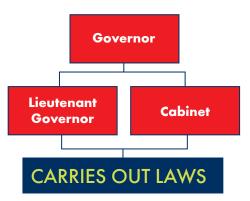
### LEGISLATIVE BRANCH



### **Executive Branch**

The executive branch carries out and enforces laws. The governor of each state heads the executive branch.

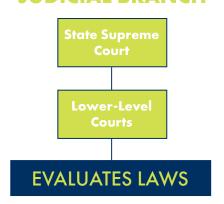
### **EXECUTIVE BRANCH**



### **Judicial Branch**

The judicial branch interprets the meaning of laws, applies laws to individual cases and decides if laws violate the Constitution. The Constitution and laws of each state establish the state courts. The state Supreme Court is usually the highest court in the state. Some states also have an intermediate court of appeals. Below these appeals courts are the state trial courts, circuit courts or district courts. States also usually have courts that handle specific legal matters.

### JUDICIAL BRANCH



### Find Your Elected Officials

### **State Legislature Websites**

Every official state legislature website can be found at: www.usa.gov/Agencies/State-and-Territories.shtml

### Other Helpful Resources

### **Council of State Governments**

Founded in 1933, the Council of State Governments (CSG) serves all three branches of state government. CSG is a region-based forum that fosters the exchange of insights and ideas to help state officials shape public policy. The mission of CSG is to champion excellence in state governments to advance the common good.

#### **WWW.CSG.ORG**

### **National Conference of State Legislatures**

The National Conference of State Legislatures (NCSL) was created in 1975 and is committed to improving the quality and effectiveness of state legislatures; promoting policy innovation and communication among state legislatures; and ensuring state legislatures are a strong, cohesive voice in the federal system.

#### **WWW.NCSL.ORG**

### **National Governors Association**

Founded in 1908, the National Governors Association (NGA) is a bipartisan organization of the nation's governors. Through NGA, governors share best practices, speak with a collective voice on national policy, and develop innovative solutions that improve state government and support the principles of federalism.

#### **WWW.NGA.ORG**

### **National Lieutenant Governors Association**

Founded in 1962, the National Lieutenant Governors Association (NLGA) is the professional association for the elected officials first in line of succession to the governors. NLGA promotes the efficiency and effectiveness of the Office of Lieutenant Governor.

### **WWW.NLGA.US**

### **POSITION STATEMENTS**

The Arthritis Foundation has created several position statements that guide our advocacy work in the states and in Washington, DC.



### **Biosimilar Substitution**

#### Issue

The Affordable Care Act creates a regulatory pathway for approving a new generation of biologic medications called "biosimilars." Biosimilar medications have the potential to provide safe and effective treatment to people with arthritis at a significantly lower cost than the name-brand biologic medications.

### **Background**

For years, biologic medical products have offered tremendous therapeutic benefits to thousands of patients with arthritis and have also helped many others living with complex chronic diseases.

As a result of the Affordable Care Act, new pathways have emerged to assist in the recognition of new biologic products that may be considered "biosimilar" to a currently recognized or referenced biologic product.

This new class of biosimilars will be entering the marketplace in the near term. These complex, genetically-engineered products offer new, and hopefully more affordable, treatment opportunities for people with forms of inflammatory autoimmune arthritis. Through special review processes conducted by the FDA, some of these biosimilar products may be deemed therapeutically equivalent to or interchangeable with an original biologic or reference product.

In the future, interchangeable biosimilars recognized by the FDA may be substituted for an approved biologic. However, as both biologics and biosimilars are complex treatments requiring careful therapeutic monitoring, pathways for substitution require communication and transparency in all pharmacy transactions.

### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation that provides a pathway for biosimilar substitution and should include the following:

- Communication to the patient when substitution occurs.
- Communication to the prescriber within 48 hours of the substitution.
- Retention of substitution records for a minimum of five years.
- Permission for a physician to override substitution when patients are stable on a prescribed biologic.
- FDA approvals on biosimilar medications that are therapeutically equivalent to and interchangeable with the original biologic.
- An individualized and unique name for the biosimilar medication that is noticeably different than the referenced biologic.

January 2015



## Health Insurance Plan Formulary Transparency

#### Issue

Most health insurance plans have a website that allows consumers to compare costs and benefits as they shop for the best health care coverage. However, these websites generally do not include specific information on issues of importance for people with arthritis, such as cost sharing, prior authorization or step therapy requirements regarding specific medications.

### **Background**

Transparency in insurance health plans would benefit people with arthritis who are comparing the provisions and benefits of various insurance plans. Formulary transparency gives consumers essential care information on specific drug coverage, out-of-pocket costs, coverage limits, prior authorization requirements and step therapy protocols.

People with substantial prescription drug needs – especially those living with chronic conditions such as rheumatoid arthritis – must be able to access this information so they can select the most fitting health insurance plan. Formulary transparency makes it easier for those with serious conditions to choose a plan that will cover the prescription drugs and therapies they need.

### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation that provides formulary transparency in health insurance plans and should require the following:

- Maintain a clear, searchable listing of medications covered in a plan's formulary by drug name and disease type.
- Disclose all co-payment and co-insurance obligations for each medication.
- · Disclose special requirements for each medication, including step therapy and prior authorization.
- Disclose formulary changes on a monthly basis and within 72 hours during open enrollment.
- Provide alternative methods for reviewing formulary listings to those without Internet access.

January 2015



### Narrow Provider Networks/ Network Adequacy

#### Issue

Many people with arthritis who are enrolling in health insurance plans are learning that the availability of doctors, specialists and hospitals through those plans is extremely limited. Patients who do not have access to necessary medical care through their insurance plans are forced to use "out-of-network" providers for care. Because insurers do not pay for out-of-network care, patients only have access to care that is specific to their needs by absorbing a substantial cost-sharing obligation or by switching doctors.

### **Background**

Many health insurance plans limit the number of doctors, hospitals, facilities and services that are available to their plan enrollees. Providers in the plan's network are generally covered, and the use of a provider not within the plan is considered out-of-network and is not covered by the plan. Patients who use out-of-network providers typically pay significantly more than they would for providers in a plan – or even all of the cost without any contribution from their insurer.

A plan with few choices is considered to have a "narrow network." Some narrow networks have been identified without the availability of a nearby hospital, absence of specialists, facilities in geographically unfavorable distances from population centers, and physicians who are overbooked or not taking on new patients. The inadequacy of a narrow network to serve the diverse needs of its enrollee population can serve as a direct impediment for access to care.

The Affordable Care Act (ACA) requires all insurers providing qualified health plans through a health insurance exchange to achieve certain network adequacy requirements (45 CFR 155.1050/156.230). The ACA mandates the minimum requirements and permits the states to develop even more rigorous requirements for exchange plans. Under the ACA, insurers must:

- 1. Have a network for each plan with a sufficient number, geographical distribution and types of providers to ensure all services are accessible without unreasonable delay.
- Include in networks a sufficient number and geographical distribution of essential community providers to ensure reasonable and timely access to a broad range of such providers for low-income patients and the medically underserved.

The network adequacy requirements of the ACA are limited only to insurance acquired through the health insurance exchanges and do not apply to commercial insurance policies. Because current state laws do not specifically provide against narrow or inadequate networks, state legislation is being considered to solve the problem. While corrective legislation is pending, some state insurance commissioners have taken it upon themselves to impose adequate network requirements as a condition of offering plans in their respective states.

### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation or regulation that restricts narrow or inadequate provider networks and should provide the following:

- Insurance plans must ensure access to care in a way that does not negatively impact an enrollee's health.
- Insurance plans must ensure a minimum level of access to care based on clinical appropriateness, the nature of the specialty and the urgency of care.
- Insurance plans must ensure a sufficient number of geographically accessible health care providers for the number of enrollees in a given region.
- Insurance plans must ensure a network that includes sufficient health care providers in each area of specialty practice to meet the needs of the enrollee population.
- An insurance plan that is unable to provide sufficient access to required providers must ensure that an enrollee may obtain a covered benefit at no greater cost to the person than if the benefit were obtained from participating providers.
- Insurance plans must ensure the ability to select specialty practice health care providers within a reasonable travel time and distance taking into account the conditions for provider access in rural areas.
- Insurance plans must ensure a sufficient range of services.
- Insurance plans must not exclude any type of health care provider as a class.

October 2014



### **Out-of-Pocket Medication Costs**

#### Issue

Health insurers have historically charged fixed co-pays for different tiers of medications. As an example, the co-pays might be set at \$10/\$20/\$50 for the three tiers. Some health insurance policies are now moving vital medications (mostly biologics) into a fourth specialty tier. Specialty tiers require people with arthritis and other conditions to pay a percentage of their drug cost – often 25 percent to 50 percent – rather than a fixed dollar amount co-payment.

### Background

High cost sharing, also known as co-insurance, is a barrier to medication access for patients with chronic, disabling and life-threatening conditions and may result in serious harm. Cost sharing for prescription medications should not be so burdensome that it restricts or interferes with access to necessary medications, which can lead to negative health outcomes and additional costs to the health care system.

Since many people with arthritis also suffer with chronic diseases such as diabetes or heart disease, their monthly medication expenditures to lead productive lives can include several kinds of medications. Ensuring that people with arthritis have access to affordable quality treatments and medications is a guiding principle of the Arthritis Foundation.

### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation that limits out-of-pocket costs and should provide the following:

- Limits the cost of a 30-day supply of any single prescription medication to no more than \$150 a month.
- Limits the total aggregate monthly out-of-pocket cost for all prescription medications.
- Limits the total annual out-of-pocket expenditures for all prescription medications at a maximum of 50 percent of the Affordable Care Act (ACA) total out-of-pocket limits for an individual or family plan.

October 2014



### **Prior Authorization**

#### Issue

Before specialty drugs are dispensed, many insurance companies require a cumbersome process called prior authorization. Though each insurance plan has its own system of forms, protocols and approval procedures (and these may vary based on the medication or therapy under review), prior authorization typically causes lengthy delays, thereby restricting a patient's access to vital care.

### **Background**

Physicians must fill out a prior authorization form whenever a provider prescribes a specialty medicine or treatment that is not covered under the insurer's formulary, placing an unnecessary burden on patients, pharmacies and doctors.

Under this system, physicians and pharmacists spend many hours completing and processing these forms, and they are often forced to wait days before receiving notification of a prescription approval or denial. They must also repeatedly follow up with insurers to confirm that all the necessary paperwork has been submitted.

#### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation that would standardize prior authorization protocols and streamline patient access to vital medications and treatments. Legislation should:

- Establish a single standardized form (paper or electronic) for providers to submit prior authorization requests.
- Require prior authorization requests to be completed within 48 hours of submission or receive automatic approval.

January 2015



### Step Therapy/"Fail First"

### Issue

An increasing number of insurers are utilizing step therapy or "fail first" policies that require patients to try and fail one or more formulary-covered medications before providing coverage for the originally prescribed non-formulary or non-preferred medication.

### **Background**

Step therapy or "fail first" is the practice by insurers of requiring patients to test use of a safe, lower-cost drug or service before permitting more expensive drugs or services. Step therapy is an established benefit management tool that is used by commercial carriers, self-insured employers, Medicare Advantage/Part D programs and Medicaid.

When a patient changes insurers, or a drug they are currently taking is moved to a non-preferred status, patients may be put through the step therapy process again. Some step therapy protocols impose these requirements on stable patients.

### **Arthritis Foundation Position**

The Arthritis Foundation supports legislation that provides limitations on step therapy/ "fail first" protocols and believes the following provisions are essential to protect patients:

- Permit a prescriber to override the step therapy when patients are stable on a prescribed medication.
- Permit a physician to override the step therapy if the physician expects the treatment to be ineffective based on
  the known relevant physical characteristics of the patient and the known characteristics of the drug regimen; will
  cause or will likely cause an adverse reaction by or physical harm to the patient; or is not in the best interest of
  the patient, based on medical necessity.
- Require health insurance plans to incorporate step therapy approval and override processes in their preauthorization applications.
- Prohibit insurers from requiring insured patients from having to fail a prescription medication more than once.
- Limit any single step therapy protocol to a maximum of 60 days.
- In circumstances where an insured is changing health insurance plans, the new plan may not require the patient
  to repeat step therapy when that person is already being treated for a medical condition by a prescription drug,
  provided that the drug is appropriately prescribed and is considered safe and effective for the patient's condition.
- When a health insurance plan changes formulary design, the plan cannot limit or exclude coverage for a drug for
  an insured if the drug previously had been approved for coverage by the plan for the person's medical condition
  and the plan's prescribing provider continues to prescribe the drug for the medical condition.

October 2014

### **MODEL LEGISLATION**

Our model state legislative language can help you engage on state issues and achieve successes in your home state. These model bills were created in consultation with other organizations who share our goal of better access to health care for all. Share them with your elected official when you begin to discuss access issues in your state.

### **Step Therapy Legislation**

### **Section 1. Legislative Findings**

- (A) The legislature finds that health insurance plans are increasingly making use of step therapy protocols under which patients are required to try one or more prescription drugs before coverage is provided for a drug selected by the patient's health care provider.
- (B) The legislature further finds that such step therapy protocols, where they are based on well-developed scientific standards and administered in a flexible manner that takes into account the individual needs of patients, can play an important role in controlling health care costs.
- (C) The legislature further finds that, in some cases, requiring a patient to follow a step therapy protocol may have adverse and even dangerous consequences for the patient who may either not realize a benefit from taking a prescription drug or may suffer harm from taking an inappropriate drug.
- (D) The legislature further finds that, without uniform policies in the state for step therapy protocols, patients may not receive the best and most appropriate treatment.
- (E) The legislature further finds that it is imperative that step therapy protocols in the state preserve the heath care provider's right to make treatment decisions in the best interest of the patient.
- (F) Therefore, the legislature declares it a matter of public interest that it requires health insurers to base step therapy protocols on appropriate clinical practice guidelines developed by independent experts with knowledge of the condition or conditions under consideration; that patients be exempt from step therapy protocols when inappropriate or otherwise not in the best interest of the patients; and that patients have access to a fair, transparent and independent process for requesting an exception to a step therapy protocol when appropriate.

### Section 2. Definitions

- (A) "Clinical practice guidelines" means a systematically developed statement to assist health care provider and patient decisions about appropriate health care for specific clinical circumstances and conditions.
- (B) "Clinical review criteria" means the written screening procedures, decision abstracts, clinical protocols and practice guidelines used by an insurer, health plan or utilization review organization to determine the medical necessity and appropriateness of health care services.
- (C) "Step therapy protocol" means a protocol or program that establishes the specific sequence in which prescription drugs for a specified medical condition and that are medically appropriate for a particular patient are covered by an insurer or health plan.
- (D) "Step therapy override determination" means a determination as to whether a step therapy protocol should apply in a particular patient's situation, or whether the step therapy protocol should be overridden in favor of immediate coverage of the health care provider's selected prescription drug. This determination is based on a review of the patient's request for an override, along with supporting rationale and documentation.
- (E) "Utilization review organization" means an entity that conducts utilization review, other than an insurer or health plan performing utilization review for its own health benefit plans.

### Section 3. Clinical Review Criteria

- (A) Requirements and Restrictions. Clinical review criteria used to establish a step therapy protocol shall be based on clinical practice guidelines that:
  - (1) Recommend that the prescription drugs be taken in the specific sequence required by the step therapy protocol;
  - (2) Are developed and endorsed by an independent, multidisciplinary panel of experts not affiliated with an insurer, health plan or utilization review organization;

- (3) Are based on high quality studies, research and medical practice;
- (4) Are created by an explicit and transparent process that:
  - i. Minimizes biases and conflicts of interest;
  - ii. Explains the relationship between treatment options and outcomes;
  - iii. Rates the quality of the evidence supporting recommendations; and
  - iv. Considers relevant patient subgroups and preferences; and
- (5) Are continually updated through a review of new evidence and research.

### **Section 4. Exceptions Process Transparency**

- (A) Exceptions Process. When coverage of a prescription drug for the treatment of any medical condition is restricted for use by an insurer, health plan or utilization review organization through the use of a step therapy protocol, the patient shall have access to a clear and convenient process to request a step therapy override determination. An insurer, health plan or utilization review organization may use its existing medical exceptions process to satisfy this requirement. The process shall be made easily accessible on the insurer's, health plan's or utilization review organization's website.
- (B) Exceptions. A step therapy override determination request shall be expeditiously granted if:
  - (1) The required prescription drug is contraindicated or will likely cause an adverse reaction by physical or mental harm to the patient;
  - (2) The required prescription drug is expected to be ineffective based on the known relevant physical or mental characteristics of the patient and the known characteristics of the prescription drug regimen;
  - (3) The patient has tried the required prescription drug while under their current or a previous health insurance or health benefit plan, or another prescription drug in the same pharmacologic class or with the same mechanism of action and such prescription drug was discontinued by a health care provider due to lack of efficacy or effectiveness, diminished effect or an adverse event;
  - (4) The required prescription drug is not in the best interest of the patient, based on the health care provider's determination of medical appropriateness; or
  - (5) The patient is stable on a prescription drug selected by their health care provider for the medical condition under consideration.
- (C) Effect of Exception. Upon the granting of a step therapy override determination, the insurer, health plan or utilization review organization shall authorize coverage for the prescription drug prescribed by the patient's treating health care provider, provided such prescription drug is a covered prescription drug under such health insurance or health benefit plan policy or contract.
- (D) Limitations. This section shall not be construed to prevent:
  - (1) An insurer, health plan or utilization review organization from requiring a patient to try an AB-rated generic equivalent prior to providing coverage for the equivalent branded prescription drug; or
  - (2) A health care provider from prescribing a prescription drug that is determined to be medically appropriate.

### Section 5. Regulations

Notwithstanding any law to the contrary, the [Division of Insurance] shall promulgate any regulations necessary to enforce this Act.

### **Section 6. Enactment**

This Act shall apply only to health insurance and health benefit plans delivered, issued for delivery or renewed on or after January 1, 20XX.

### **Medication Stability Legislation**

An act to prohibit health insurance plans from requiring pharmaceutical switching of medically stable patients.

### Purpose of the Act:

To prohibit a health insurance plan from limiting or excluding coverage of a prescription drug for a medically stable patient with a complex or chronic medical condition or a rare medical condition, or requiring or encouraging a medically stable patient with a complex or chronic medical condition or a rare medical condition to switch a prescription drug without the express written consent of the health care provider prescribing the drug.

### **Section 1. Definitions**

- 1. "Complex or chronic medical condition" means a physical, behavioral or developmental condition that:
  - a) May have no known cure;
  - b) Is progressive; or
  - c) Can be debilitating or fatal if left untreated or undertreated.
- 2. "Rare medical condition" means a disease or condition that affects fewer than:
  - a) 200,000 individuals in the United States, or
  - b) Approximately 1 in 1,500 individuals worldwide.
- "Medically stable" means a determination made by the prescribing health care provider, and based upon the prescribing health care provider's clinical expertise, taking into account the patient's condition and response to treatment.
- 4. "Switch" means a change in a patient's prescription drug, not originated by the prescribing health care provider, from what was originally prescribed to another prescription drug, for non-medical reasons.

### **Section 2. Prohibitions**

- 1. No health plan or pharmacy benefit manager shall limit or exclude coverage of a prescription drug for a medically stable patient with a complex or chronic medical condition or a rare medical condition, or require or encourage a medically stable patient with a complex or chronic medical condition or a rare medical condition to switch a prescription drug, without the express written consent of the health care provider prescribing the drug that is subject to the switch.
- 2. Nothing in this section prohibits a health plan or pharmacy benefit manager, by contract, written policy or procedure or any other agreement or course of conduct, from requiring a health care provider to effect generic substitutions of prescription drugs.

### **Section 3. Enforcement**

The Insurance Commissioner shall promulgate regulations for the administration and enforcement of this Act.

### Section 4. Effective Date

This Act shall become effective on January 1, 20XX.

We want to
work with you to
fight for timely access
to medications and a
cure for arthritis.

FOR MORE INFORMATION,
CONTACT ADVOCACY@ARTHRITIS.ORG.

BECOME AN ADVOCATE AT

WWW.ARTHRITIS.ORG/ADVOCACY.

## Conclusion

Thank you for helping the Arthritis Foundation speak out on behalf of the millions of Americans with arthritis.

As you've read in these pages, the Arthritis Foundation wants to help you be your own best Advocate, whether in your personal life, your community or within the halls of Congress. If you are reading this toolkit, then you've taken an important first step to becoming an effective arthritis Advocate.

Sandie G. Briss

Sandie Preiss
Vice President, Advocacy and Access
Arthritis Foundation



We hope you find these tools helpful. They are building blocks to support your advocacy efforts – because you are the most important piece of the movement to cure arthritis. We believe you possess the ability to have a significant impact on the legislation, policies and rules that can drastically affect the health and well-being of individuals in your community and across the nation.

Once you've put these tools into action, we want to hear about your advocacy experiences. Whether you have helped a loved one navigate a health care system, had your letter to the editor published or formed a relationship with an important policymaker, we want to hear your story. We also want to help you achieve your goals.

The Arthritis Foundation joins with like-minded organizations to develop policy positions and advocacy campaigns so that the voices of people with arthritis are amplified. Many chronic diseases share the same access issues that people with arthritis experience. Coming together at the state and federal levels with one voice makes it easier for policymakers and elected officials to hear our stories and understand our needs.

### **Federal Coalitions**

The Arthritis Foundation is an active member of each of the following federal coalitions.

### **Coalition for Health Funding**

Largest coalition dedicated to public health funding; more than 80 members; advocates for top line funding of the U.S. Department of Health and Human Services (HHS) agencies; also heavily involved in sequestration and broader budget issues; sends out daily member updates on appropriations issues and events.

### Friends of Centers for Disease Control (CDC)

Advocates for CDC funding; annual meeting with the CDC director and staff every year; sends updates on CDC funding bills and news.

### Centers for Disease Control and Prevention (CDC) Arthritis Program Coalition

Coalition led by the Arthritis Foundation dedicated to preserving and ultimately growing funding for the CDC Arthritis Program.

#### **Coalition for Accessible Treatments**

Informal coalition created by the Arthritis Foundation and the American College of Rheumatology to advocate for the Patients' Access to Treatments Act (PATA); monthly calls; co-chaired by the Arthritis Foundation.

### **Patient Access to Community Treatment**

Coalition advocating for patient access to community-based care; major bills are HR 800/S 806 (Medicare prompt pay) and HR 1416 (eliminates Medicare sequestration cuts).



### **Pediatric Subspecialty Loan Repayment Program Coalition**

Advocates for reauthorization and funding of the pediatric subspecialty and mental health loan repayment program; currently exploring other options to get subspecialty loan repayment funded.

### **MAPRx Coalition**

Advocates for Medicare Part D patient protections; considers a variety of issues, including benefit design, premiums and medication therapy management.

### **Rx For US**

Coalition led by National Association of Chain Drug Stores that advocates for patient access to medications. Membership includes a mix of provider groups, patient groups and pharmacy groups, which meet three times a year.

### **National Coalition of Autoimmune Patient Groups**

Coalition of autoimmune patient and provider groups that advocate for issues related to specialty drugs, research funding and access to providers and treatment.

### National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition

Advocates on behalf of NIAMS; holds meetings with NIAMS staff; conducts an annual site tour for Capitol Hill staff; holds briefings and other events on the Hill each year.

### Ad Hoc Group for Medical Research

Network of groups interested in medical research; holds periodic town halls to discuss issues and strategy; sends a weekly roundup of research news and events; advocates for topline National Institutes of Health (NIH) funding.

### Friends of Health Resources and Services Administration (HRSA)

Advocates for topline HRSA funding; annual meeting with the HRSA director and staff every year; sends updates on HRSA funding bills and news.

### Graduate Medical Education (GME) Coalition

Coalition led by the American Association of Medical Colleges, advocating for raising or eliminating the caps on federally-funded GME slots, GME reform and increasing resources for GME.

### Regulatory Education and Action for Patients (REAP) Coalition

Patient advocacy coalition dedicated to ensuring that the patient voice is represented in regulatory affairs, and that patients are educated about rules and policies that affect them.

### **Patients for Biologic Safety and Access**

Patient-specific coalition led by the Immune Deficiency Foundation, dedicated to ensuring patient safety protections in biosimilar policies, including advocating for unique names.

### **Coalition for Clinical Trials Awareness**

Coalition dedicated to raising public awareness of clinical trials and educating patients on why they should participate in medical research.

### **Medicare Therapy Cap Coalition**

Coalition lead by the American Physical Therapy Association, dedicated to eliminating caps on coverage for physical therapy services in Medicare.

### **State Legislative Coalitions**

The Arthritis Foundation is an active member of each of the following state legislative coalitions.

### State Access to Innovative Medicines (State-AIM)

Coalition focused on out-of-pocket costs, specialty tiers and step therapy; also seeks to bring together likeminded organizations.

### National Health Council Affordable Care Act State Implementation Workgroup

Coalition that works to create state legislation and regulations to ensure a patient-focused insurance marketplace.

### **Coalition Against Switching Medications for Stable Patients**

Coalition that advocates against switching a stable patient's proven treatments because of non-medical, purely economic policies of the insurer.

#### Cap the CoPay

Coalition that advocates for creating a fair, economical solution ensuring that patients have access to the appropriate treatment options for their chronic conditions

# 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, treaty 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:** The primary form of legislative measure used to propose law. Depending on the chamber of origin, bills begin with a designation of either H.R. or S.

**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).

**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 Housepassed and Senate-passed versions of a measure.

**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).

**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.

**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.

**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.

**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.

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

**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.

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

### Glossary | Social Media

**BITLY:** Website that shortens and tracks click rates for URLs. (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 Twitter)

**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, Twitter, 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: @preventcancer (Twitter)

**HASHTAG:** A type of tag used to find posts about a specific topic. Example: #arthritis#RA (Facebook, Twitter, 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, Twitter, 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 something to your profile. (Facebook, Instagram, YouTube)

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

**RETWEET:** To repost a tweet that someone else has tweeted. (Twitter)

**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)

FOR MORE INFORMATION,
CONTACT ADVOCACY@ARTHRITIS.ORG.

BECOME AN ADVOCATE AT WWW.ARTHRITIS.ORG/ADVOCACY.



