Voices Up, Barriers Down:
Your Guide to Grassroots Advocacy

Arthritis Advocacy Toolkit
“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.”

- Ann M. Palmer, President and CEO, Arthritis Foundation
As a Champion of Yes, you can help knock down barriers to easy and affordable care and use your Yes attitude to make a difference. Amplify your message by adding your voice to ours. The actions you take will help increase program and research funding, and remove barriers to treatments that people with arthritis need. Together, we can make a positive impact on your life and the lives of many others.
The Arthritis Foundation is boldly pursuing a cure for America’s #1 cause of disability, while championing the fight against arthritis with life-changing resources, science, advocacy and community connections.

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. Through our effective and committed advocacy network, the Arthritis Foundation is working to address key issues on both the state and federal levels with lawmakers, insurers and regulators, helping ease people’s burdens so they can reach their goals.

SCIENTIFIC DISCOVERY | For Better Treatments and a Cure
Science holds the key to finding better treatments and one day a cure for the more than 50 million Americans with arthritis and related diseases. On their behalf, 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. The Foundation’s 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
The Arthritis Foundation is expanding our reach to assist even more people with arthritis. We offer trusted information, powerful health tracking tools and ways to connect with others. The Foundation works with health care providers and other partners to strengthen our educational and interactive offerings. We’ve also built a state-of-the-art digital enterprise so people with arthritis can customize their 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, nearly 300,000 children have JA and other rheumatic diseases. Multiply that by their parents, siblings, extended family and others, and the number of people affected is astronomical. 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, ensuring easy access to life-changing resources, community and care.

COMMUNITY AND CONNECTIONS | Making a Difference
The Arthritis Foundation’s social media communities and fundraising events bring us all together. We help individuals and families with arthritis form meaningful connections and find ways to give back – getting the support they need while supporting others.
Our tools and resources help people with arthritis live life to its fullest – easing their pain and illuminating a path toward wellness.

**Arthritis Support Networks**
A nationwide network of peer-led, local support groups that bring people together for fun and informative events. You will learn as a group how to not just survive life with arthritis, but thrive.

[Find a network near you >](#)

**Arthritis Today**
A magazine tailored to you provides news and advice on nutrition, exercise, medication, weight control and more form the world’s top doctors and health experts. Available in both print and digital format.

[Learn more and subscribe >](#)

**Arthritis Helpline**
Licensed clinical social workers provide assistance on a variety of topics, such as access to care and financial assistance.

[Call toll-free at 1-844-571-HELP (4357)](#)

**Arthritis Resource Finder**
Your one-stop tool to find local health care providers, fitness programs and other essential arthritis resources right in your community. All you have to do is enter your zip code.

[Search for local resources >](#)

**Nationwide There are Many Local Events you can Attend**
- Walk to Cure Arthritis in the spring
- Jingle Bell Run in the winter
- Juvenile arthritis family days and camps in the summer

[Find out about local events >](#)

Visit [arthritis.org](https://arthritis.org) to find out more about events that may be planned in your area.
Living with arthritis is enough to deal with day to day. Who needs the added challenge of navigating a complex health care system to get the treatments required to manage it?

The Arthritis Foundation is constantly listening to our community to identify current areas of concern — areas where we need to take action to improve lives today. As we listen, we are hearing a mounting concern from our community about their ability to access affordable medications in a timely manner. For some, understanding the health care system is as difficult as understanding their disease. It’s our job to help the arthritis community navigate the complex health care issues confronting them.

**Prescription For Access**

To proactively address the concerns of our constituents, we have launched a new initiative called Prescription for Access, and we have invited and will continue to invite key leaders from the pharmaceutical industry, insurers, pharmacy benefit managers, health care providers and key policymakers to create a shared understanding of the issues people with arthritis are facing and to formulate a new agenda for the Foundation centered on real-time short- and mid-term solutions.

**Bringing Together Patients, Providers and Other Decision Makers**

Prescription for Access brings together patients, providers and other decision makers to have open dialogue about the issues of accessing treatments that people with arthritis need and create change in health care. We’re fighting to make arthritis care more accessible and less burdensome for millions.

**Prescription for Access Tools and Resources**

- **Your Coverage, Your Care Toolkit**
  Explore our powerful new toolkit created to help you better understand health coverage options, learn how to get the arthritis care you need and manage claim denials.

- **5 Things You Can Do Now to Improve Ease and Access to Care**
  Learn five tangible things you can do now to overcome barriers and improve your health care in the coming year.

- **Patient Principles for Health Care**
  All people, including those with arthritis, deserve a transparent health care system that allows them to make informed decisions. If the following principles are adopted system-wide, we will achieve this goal.

- **Legislative Patient Principles for Health Reform**
  This one-page summary of the Patient Principles for Health Care is an excellent conversation starter and leave behind for legislators and policymakers.

Visit the [Prescription for Access toolkit](#) on our website to learn more!
“As a rheumatologist, epidemiologist, researcher and chair of the Arthritis Foundation’s board of directors, I understand the profound and devastating effects of arthritis, and the Foundation’s role in influencing policies and strategies to improve access to care and ultimately find a cure. Our **ADVOCATES** and **AMBASSADORS** play a **CRITICAL ROLE** by using their **VOICES AND PERSONAL ARTHRITIS STORIES**, helping legislators, regulators and other policymakers better understand the challenges people with arthritis face – and how we all can knock down barriers to care.”

- Rowland W. (Bing) Chang, MD, MPH, Chair, Arthritis Foundation Board of Directors
How the Arthritis Foundation Can Help You

When you join the movement, you become part of the answer. Our events and volunteer opportunities allow you to form meaningful connections and find ways to give back—getting the support you need, while supporting others.

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

**ADVOCATE**
Sign up and share your story as an Arthritis Foundation Advocate or Ambassador and let your voice be heard.

**VOLUNTEER**
Find your closest Arthritis Foundation office and get involved in local activities and events.

**JOIN**
Join the Arthritis Foundation today with a gift of just $20 and start enjoying amazing membership benefits like a one year subscription to the Arthritis Today magazine and member tools like Your Exercise Solution® (YES), the Arthritis Resource Finder and the Better Living Toolkit!

**DONATE**
Too few people know the truth about arthritis—that it’s a widespread, costly and debilitating disease. By spreading awareness, speaking out for affordable care and funding groundbreaking research for a cure, the Arthritis Foundation is leading the fight for a better life with arthritis. Make a gift today and help us find a cure.

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.
Advocacy 101

The key to success in changing government policies and funding is through grassroots advocacy. Our Advocates are the Arthritis Foundation’s chief resource for making positive changes in our government. 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 your story!
Whether you are attending Arthritis Foundation’s Advocacy Summit in Washington, DC, or meeting with your state officials, advocating for arthritis issues throughout the country is essential to making medications more affordable, funding new research and ultimately finding a cure.

**Top Three Advocate Priorities**

1. **RESEARCH FOR A CURE**  
   Affordability of medications and financial concerns

2. **MANAGING CHRONIC PAIN**

3. **ACCESS TO INSURANCE COVERAGE AND PROVIDERS**

**Top Arthritis-Related Challenges:**

- Affordability of medications and financial concerns
- Burdensome prior authorization requirements and concerns about access to providers

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

**Types of Advocacy**

**PERSONAL**  
Represent and speak up for yourself and your loved ones. Be informed about the issues and take an active role in positively impacting policy that will allow you and your community to live a healthy, productive life.

**COMMUNITY**  
With your help, we can work together to build the strongest community possible. You can be the voice for the interests and concerns of your neighbors.

**MEDIA**  
Use your local communication channels to increase public awareness and influence public interest in arthritis issues through publication letters, social media, interviews and other communication platforms.

**LEGISLATIVE**  
Reach out to elected officials at the local, state or federal level, to educate and influence them on important legislative decisions. Every American 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.
As a citizen of the United States of America, it is your right and responsibility to take an active role in our government. You can do so as an Arthritis Foundation Advocate! Your first step is understanding the basic structure of our civic system. There are three levels of government you can engage with:

**FEDERAL**
If you want to engage 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 engage 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**
If you want to engage at a local level, you can notify your local elected officials, like your town’s mayor or council member.

Elected officials at all levels of government represent the members of their community called **constituents**. As a constituent, you have specific elected officials based on where you live.

Find your elected officials on our website - go to our Action Center and use the **Find Officials** tool.
Advocacy: Where to Begin
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 story, you have the power to help shape public policy.

1. Claim Your Title
   Use this guide to determine the best way for you to join our advocacy army, what title might work best for you, and what your responsibilities will be in our grassroots network.

2. Identify Your Issue
   Use these prompts to help you determine the priority issues you will use to tell your arthritis story when advocating.

3. Build Your Advocacy Plan
   Outlining your goals and developing a strategy to achieve them is an essential part of advocacy. These guidelines will help you get there.

4. Take Action!
   Once you have completed these prompts, you will be ready to take action. Together we will conquer arthritis!

5. Preparation Tools
   The Arthritis Foundation Advocacy and Access team is here to help you! We have prepared materials available on our website, ready for you to use whenever you need them!

Claim Your Title
The first step is easy. Sign up to join our army of more than 150,000 Advocates and Ambassadors. When you join us, you’ll have access to the tools and resources that help you tell your story and stay up to date on advocacy news and events. There are many ways to advocate, so your first step is determining the right title for yourself.

ADVOCATE
Advocates help improve the lives of people with arthritis and are the backbone of our grassroots network. Advocates:
- Receive the monthly Advocacy in Action newsletter
- Participate in our exclusive Advocate Webinar Series each month
- Engage with elected officials through periodic Action Alerts when important arthritis-related issues are debated on Capitol Hill and in state legislatures
**AMBASSADOR**

Ambassadors are volunteers who serve as pivotal links between the Arthritis Foundation and members of Congress. Ambassadors:

- Receive the same benefits and resources as Advocates
- Develop relationships with elected officials and their staff
- Complete Ambassador assignments that help strengthen relationships with elected officials and advance legislation
- Attend the online Ambassador Briefing every other month for an advocacy news update, special guest presentations and new Ambassador assignments

**JUNIOR AMBASSADOR**

Junior Ambassadors are teens, between 13 and 17 years old, who raise awareness and represent the nearly 300,000 kids in the U.S. who have arthritis and other rheumatic diseases by sharing their arthritis story. Junior Ambassadors:

- Bimonthly advocacy training
- Help raise awareness with policymakers
- Receive the Junior Ambassador newsletter

**PLATINUM AMBASSADOR**

Platinum Ambassadors are our top-line Ambassadors who complete extra activities and raise funds to support the Foundation’s mission. Platinum Ambassadors:

- Fulfill the requirements of Ambassadors
- Complete four bonus activities throughout the year
- Raise $1,000 or more for the Arthritis Foundation

**Identify Your Issues**

**YOU AND ADVOCACY**

What motivates you to advocate for arthritis? What role does arthritis play in your personal story?

- Do you or a loved one live with arthritis?
- What issues do you face as a result of arthritis? High cost of medicines? Narrow networks for your insurance providers? Step therapy or fail first requirements?
- Are you unable to work or live fully on a daily basis because of arthritis or a related condition?
- Do you want to find better treatments and a cure for arthritis?

Your story can impact legislation and policies that affect people with arthritis. Your elected officials need to hear your story and learn about the issues you face due to arthritis. When you share your story, our country’s leaders are better able to represent your needs when major policy decisions are being made.

**NOW THAT YOU’VE DECIDED TO TAKE A STAND AND LEND YOUR VOICE TO PARTICULAR ISSUES, YOU HAVE TO DETERMINE WHAT TO DO NEXT AND WHO YOU NEED TO ENGAGE.**
Build Your Advocacy Plan

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. Without your voice, elected officials have no way of knowing about life’s daily challenges for people with arthritis.

Now that you have identified the issue for which you want to build an advocacy campaign, outline your goals and list the steps you will take to be successful. You can start with outlining an advocacy plan!

Policy changes and enacting new laws take time, so be patient. You can make the greatest impact on policy with a thoughtful, planned approach to advocacy. While a full plan might include dozens of steps, building yours can be as simple as the following example:

![Example Advocacy Plan]

**ISSUE:** High Costs of Medications

**GOAL:** Increase access to affordable medications

**ACTION:** Advocate for legislation in my state that will increase access to medications by limiting copays

** BRAINSTORM TACTICS:**

- Reach out to state-based patient advocacy organizations 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 with them by sharing your story.

- Find out if other legislation has been passed that limits copays. If so, share them with elected officials 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. You can find this information in our Arthritis Foundation State Fact Sheets located on our website under Advocacy Tools and Resources. These fact sheets make great leave-behind materials for your elected officials. Print out a copy of your home state’s fact sheet today!

- 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, maybe as a letter to the editor or an op-ed. The more visibility your issue gets, the better!

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

Now that you have your advocacy plan prepared, you’ll need to prepare your pitch for elected officials! Putting as many pieces of the puzzle together yourself before approaching your elected officials increases your chance of success. Elected officials want to have as much information as possible so they can make an informed decision about your request.

Your pitch should include answers to the following questions:

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

HELPFUL HINT: PREPARING A ONE-PAGE DOCUMENT OR “LEAVE-BEHIND” FOR YOUR ELECTED OFFICIAL THAT SUMMARIZES YOUR POSITION AND HOW YOUR ISSUE AFFECTS THEIR CONSTITUENTS REALLY MAKES A GREAT IMPRESSION.

REMINDERS

You can have the greatest impact on policy when you do your homework. Do some research on your elected officials so that when you have the opportunity to meet them, you are prepared to make a good impression. Make sure while you’re preparing your pitch that you know the answers to the following questions:

- Who are your elected officials?
- What political party do your elected officials belong to?
- Which committees do your elected officials sit on? Could these committees be helpful in your advocacy plan?
- How do your elected officials tend to vote or lean on certain issues?
- What issues are most important to your elected officials?
- How does your issue affect people who your elected officials represent?

Now it’s time to take action by presenting your pitch to elected officials! Whether you call, email, write a letter or meet with your elected official (or their staff) in person, remember that you want to educate and persuade them by sharing your story. There may be obstacles along the way — don’t give up. You have an important story to tell that can make a positive impact on legislation and policy.
Preparation Tools

Don’t forget, the Arthritis Foundation’s Advocacy and Access team wants to help you be the best Advocate possible! We’ll work with you in making preparations to take action. Simply visit our website and look through our resources or email advocacy@arthritis.org with any questions or concerns. Here are some sample materials we’ve prepared to make your job easier.

HELPFUL HINT: Preparing a one-page document or “leave-behind” for your elected official that summarizes your position and how your issue affects their constituents really makes a great impression.

Find Elected Official Tool

Find your elected officials quickly by entering in your address.

State Fact Sheet

Our State Fact Sheets present constituent specific data for your elected officials in an easy-to-read format.

Action Alerts

Our action alerts allow you to reach out to your elected officials with pre-populated messages that can be sent in five minutes or less.

Reporting Form

We also want to hear your feedback once you’ve met with your elected officials! Complete this reporting form and send it to advocacy@arthritis.org so we can work together to conquer arthritis.
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.

<table>
<thead>
<tr>
<th>Personal</th>
<th>Community</th>
<th>Media</th>
<th>Legislative</th>
<th>Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruit your friends and family to become Advocates</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand how the changing health care landscape impacts you and your family</td>
<td>✔</td>
<td></td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Write a letter to the editor</td>
<td>✔</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Contact your elected officials in support of legislation</td>
<td>✔</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Encourage your employer to provide a wellness policy</td>
<td>✔</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Collect signatures for a petition to your elected officials</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encourage family, friends and neighbors to take care of themselves</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write an op-ed piece</td>
<td>✔</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Stay up to date on arthritis-related legislation at state and federal levels</td>
<td>✔</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Start a team for your local Jingle Bell Run</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work with your local government agency to develop hiking and bike trails</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stay up to date on news stories and utilize social media to educate others</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
“There is no substitute for that feeling of satisfaction you get when you are able to obtain your legislator’s support on a bill, or when a legislator recalls your story the next time you see them. The power you have as an advocate can make all the difference in getting a bill over the finish line.”

- Ted Cadwell, Chair, National Advocacy Committee
Engage

Engaging in advocacy is easy! Our army of Advocates is here to support you in taking your first step. 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.
Easy ways to engage throughout the year:

1. Take Action from Home
2. Publication Letters
3. Calling Elected Officials
4. Visiting Elected Officials
5. Writing Elected Officials
6. Social Media
7. Recruiting New Advocates
8. Engagement Through the Year
Take Action From Home

Take action today - use the Action Center on our website to learn who your elected officials are, what opportunities we have to advocate from home, federal and state legislation, and more. It has never been easier to advocate for arthritis. For a mobile friendly experience, please download the VoterVoice app on iTunes and Google Play and use the key words “Arthritis Foundation” to find our page.
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

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

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

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

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

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

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

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

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

**HAVE SOMEONE REVIEW YOUR WRITING.** Make sure your writing is clear and effective. If your op-ed is published, send a copy to your elected official’s office.
July 19, 2018

To Whom It May Concern,

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

Arthritis impacts more than 300,000 children nationwide. Alison’s life changed when she was able to get excellent medical care and medication that helps her lead a normal life. Without her medication, she needed help dressing herself, tying her shoes, brushing her teeth, and fastening her seatbelt. She did not play outside with her sisters because her joints hurt. She cried and complained of pain every day. Because of her medications and excellent medical care, Alison now leads a normal life. She attends Brighton Middle School, rides her horse on the drill team at Old West Special Trails, volunteers with Trailblazers to help those with special needs experience equine therapy, and loves to play outside with her sisters and her dog. Biologics, although very expensive, changed her life. Please support legislation that will limit out-of-pocket costs for these important life-changing medications.

Sincerely,

K Moschitta
Keith Moschitta
Harrisburg, Pennsylvania
Op-Ed

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

Writing Tips

**DO YOUR HOMEWORK.** Check the publication’s website for guidelines on letters to the editor so you can make sure your letter meets their requirements. This information is usually located under the opinion section on the publication’s website.

**INCLUDE YOUR NAME, ADDRESS AND PHONE NUMBER.** Provide your name, address, email address and phone number, and 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 to 800 words.

**KEEP IT SIMPLE.** Remember, not everyone will have a thorough understanding of your topic. Keep your writing simple and avoid acronyms and complicated language.

**MAKE IT RELATABLE.** Choose a topic that relates to current events and explain how this topic impacts your community. Use your op-ed to tell your personal story and engage your audience.

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

**MAKE A SPECIFIC CALL TO ACTION.** Close your piece by encouraging your readers to call their elected officials and ask them to vote “yes” or “no” on a specific piece of legislation or policy.

**HAVE SOMEONE REVIEW YOUR WRITING.** Make sure your writing is clear and effective. If your op-ed is published, send a copy to your elected official’s office.
“Be logical with biologics”

By Nikki Domers

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

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

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

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

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

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

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

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

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

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

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

Domers lives in Barberton. She is an Arthritis Foundation Ambassador for Ohio.
There are often times when it’s appropriate and important for constituents to contact their elected officials in support of or in opposition to an issue or piece of legislation. Calling your member of Congress or state legislator is an effective way to advocate, especially when they are making a policy decision, an important vote is coming up or you’d like to see action on a piece of legislation.

THE ARTHRITIS FOUNDATION CAN PUT YOU IN TOUCH WITH THE SPECIFIC STAFF MEMBER YOU NEED TO SPEAK WITH ABOUT AN ISSUE. CONTACT ADVOCACY@ARTHRITIS.ORG FOR MORE INFORMATION.

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

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

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

Hello. My name is ___ name ___
and I am a constituent of ___ Senator/Representative ___.
May I please speak with the legislative aide who handles issues related to ___ health care/arthritis ___?

ONCE YOU’RE CONNECTED WITH THE LEGISLATIVE AIDE, USE THIS SCRIPT TO DISCUSS YOUR ISSUE:

Hello. My name is ___ name ___
and I am a constituent of ___ Senator/Representative ___.
I am calling today about ___ bill name/bill number/issue ___, which I am an Advocate ___ for/against ___.
Do you know if ___ Senator/Representative ___ is in favor of or in opposition to this issue?

If the elected official is IN FAVOR of your position

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

Thank you for your time and work on this issue.

If the elected official is NOT IN FAVOR of your position

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

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.]

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

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

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

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

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

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

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

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

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

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

“It’s an honor to be a part of the legislative process. Telling our personal stories to decision makers demonstrates how we all have a responsibility to shape the future of this country.”

– Annmarie McMahill, Platinum Ambassador, Wyoming
FOLLOW-UP

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

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

REMEMBER: THE ARTHRITIS FOUNDATION ADVOCACY & ACCESS TEAM IS ALWAYS AVAILABLE TO SUPPORT YOU! SEND YOUR QUESTIONS TO ADVOCACY@ARTHRITIS.ORG AND WE WILL CONNECT YOU WITH THE RIGHT RESOURCES TO MAKE THE GREATEST IMPACT POSSIBLE.
As a member of the Arthritis Foundation’s army of Advocates, it is important to establish a relationship with your elected officials and their staff. A great way to do this is setting up a face-to-face meeting to discuss issues relevant to arthritis and share your personal story. While you can discuss specific legislation with your elected official, you don’t have to start there. You can simply start a conversation based on an issue or concern you have. Use this guide when reaching out to your elected official’s office to set up your meeting.

**Requesting a Visit is Easy!**

Each office has a preferred method of communication. Call the office of your elected official first and ask to speak with the scheduler. 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. They are the issue expert and have great influence with the elected official. Though you may have scheduled a meeting with the elected official, he or she 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 then. U.S. Senators typically have more than one office in their home state.

If someone will be joining you in your meeting, be sure you give the full names of all participants to the scheduler.

Be clear about what you intend to discuss. Don’t show up with surprise topics.

**Phone Call Tips**

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

**Email Tips**

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

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

Before The Meeting

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

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

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

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

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

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

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

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

— Staci Penner
Platinum Ambassador
Kansas
During The Meeting

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

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

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

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

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

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

- Quickly introduce the people at your meeting. Mention where they live and why they are attending.
- Explain your issue and highlight the top three points you’d like to get across.
- Share your personal story, along with specific examples and data to emphasize the importance of the issue or legislation you are discussing. Show your elected official why it’s relevant to his or her constituency.

**BE HONEST & OPEN-MINDED.** Be clear about your position on an issue, even if it differs from your elected official’s view. Politely ask about your legislator’s position on the issue you are discussing and why he or she holds that view. Your elected official might have a different position than yours, but by meeting with them, it’s possible to soften or even change their views. Be open-minded and polite when responding to counter arguments. Your credibility is the most important asset you have—always tell the truth. If you are asked a question and don’t have the answer, don’t make one up. Tell the person who asks the question that you will find the answer and get back to him or her.
**SHOW RESPECT.** Do not use harsh or aggressive language or make personal attacks. Do not argue. Don’t expect your elected official or his or her team to be an expert on your topic. Remember, it’s your job to educate your representative on why your issue matters and how they can help.

**DON’T COMMIT TO SOMETHING YOU CAN’T DELIVER.** If you’ve offered to send more information or materials to an elected official and their staff, do so promptly.

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

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

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

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

**After the Meeting**

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

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

“The majority of the offices I have been to have some of the same staff year after year. It’s a great thing to be able to build rapport with them, not only at the Advocacy Summit, but also throughout the year. For my representative, I not only know her DC staff, but also her Columbus staff on a first-name basis. I frequently attend events held by her, and her staff now know me and say hello. They ask about Arthritis Foundation priorities and if there is anything they can do to help. The relationship starts when you walk in the door, tell your story and continue to educate them!”

—Taylor Guerrant, Platinum Ambassador, Ohio
Letter Writing Tips

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

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

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

Writing Tips

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

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

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

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

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

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

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

**SAY THANK YOU.** Close your letter by thanking your elected official for their time and offering to answer any additional questions or providing further information. Include your contact information and sign the letter.
[Date]
The Honorable [Name]
United States Senate
[Building and Office Number]
Washington, DC 20510

Dear Senator [name],

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

At the age of 5, my daughter Amelia did as many other kids her age do – she jumped off a swing at a playground. Following that jump, her knees swelled to the point where she could barely walk. Right then, we knew we were dealing with something much more than a swollen joint. Shortly thereafter, Amelia was diagnosed with juvenile arthritis and, now 8-years-old, is one of more than 6,000 children in Indiana living with and managing the disease. She’s an amazing little girl and does not let her condition stop her from doing what she sets her mind to. It’s been a battle from the start, with Amelia being put through what is known as step therapy by our insurance company.

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

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

Sincerely,

[Signature]
John Jones
[Mailing Address
City, State, Zip]
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

Take action online - by using the Action Center on our website you can contact your official anytime
Social Media

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

WHY DO WE USE SOCIAL MEDIA?

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

What Does Advocacy Have To Do With Social Media?

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

FACEBOOK

Facebook.com/arthritis.org

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

What You Can Do:

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

Best Practices:

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

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

Users send out short (280 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:

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

Best Practices:

- If your tweets begin with a Twitter handle, use a period before the handle if you want all of your followers to see it. Without the period, it will only be sent to your elected official. Example: .@congressmember please vote for a bill that caps copays and makes medications more affordable! #advocateforarthritis
- Less is more. Tweets that don't use all 280 characters get more traction.
- Make it a conversation. Don't just tweet. Favorite and reply to tweets you find relevant and interesting.
- If you want to add a thought when retweeting, write "your comment here" RT @twitterhandle "the original tweet."
- Use hashtags so more people can find your posts. Example: #Arthritis #AdvocateForArthritis #AsktheAF
- 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:

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

Best Practices:

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

POSSIBLE POSITIVE OUTCOME: A STATE LEGISLATOR SUPPORTS LEGISLATION IN YOUR STATE BASED ON YOUR APPEAL.
INSTAGRAM
@arthritisfoundation

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

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

Best Practices:
- 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 #AdvocateForArthritis #AsktheAF

POSSIBLE POSITIVE OUTCOME: THE PHOTO FROM YOUR LAST MEETING WITH A LEGISLATOR MAY INSPIRE SOMEONE TO #ADVOCATEFORARTHRITIS!
Join the Ambassador Program

There are many options for you to stay involved in advocacy year-round!

YOU CAN 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 54 million Americans living with doctor diagnosed arthritis. Ambassadors are brought together with a bimonthly webinar and are given activities that help build and foster relationships with their state and federal legislators.

• The Ambassador year runs from October to September.
• Any new Ambassadors must fill out an online form to become an Ambassador. New Ambassadors are required to attend a New Ambassador Orientation.
• Ambassadors must reside in the state and district they advocate in. For instance, an Ambassador must live in Chicago to vote in Illinois. Same goes for advocacy.

REMEMBER TO REPORT YOUR MONTHLY ACTIVITIES IN THE AMBASSADOR REPORTING CENTER.

“The Ambassador program gives people an opportunity to channel passion into action and make a difference on the state and federal levels for everyone with arthritis.”

- Margo Deihl, Ambassador, Fredericksburg, VA
2018 Arthritis Foundation Ambassador Program Bonus Activities

To become a Platinum Ambassador, Ambassadors must complete 1 option of all regular activities, plus 4 bonus activities and raise $1000. Ambassadors who complete all options in a given month will be awarded a bonus activity.

1. Serve as a State Advocacy Chair.

2. Serve on a State Advocacy Committee.

3. Accept an invitation, should it be made, to present at a congressional or state briefing, hearing, or with a state or federal agency or legislature.

4. Accept an invitation, should it be made, to present an advocacy related presentation at an Arthritis Foundation event.

5. Volunteer at the JA Conference Advocacy Booth.


7. Lead a Walk to Cure Arthritis or Jingle Bell Run team that raises at least $1,000. You may participate virtually in the Walk to Cure Arthritis or Jingle Bell Run nearest you, should one not be within driving distance. The $1,000 fundraising goal is in addition to the $1000 to be a Platinum Ambassador.

8. Volunteer in the coordination and / or training at a state capitol day or local advocacy training.

9. Recruit 50 Advocates outside of an Arthritis Foundation event.

10. Serve as the Advocacy Chair for an Arthritis Foundation event. This includes, but is not limited to, Walk to Cure Arthritis, Jingle Bell Run, Bone Bash, Galas.

11. Separate from an assigned activity, meet with your state or federal representative or staff in your hometown and share with them at least one of the Arthritis Foundation’s state or national advocacy priorities outside any scheduled Ambassador activities.

12. Outside any scheduled Ambassador activities, attend a Town Hall or Tele-Town Hall meeting with a state or federally elected official.

13. Appear in a local or online newspaper for your efforts raising awareness about Arthritis Foundation advocacy.

14. Speak with a local community group about Arthritis Foundation advocacy.

15. Successfully persuade a state, federally elected official or mayor to attend an Arthritis Foundation event.

16. Organize a visit with an elected official and an area rheumatologist in their clinic to discuss Arthritis Foundation advocacy.

17. Serve as a patient grant reviewer to a state or federal health agency or committee such as the Patient Centered Outcomes Research Institute or Department of Defense.


20. Create a blog about being an Ambassador and blog about state and federal issues and discuss the Ambassador program in general.

21. Use social media twice a month at a minimum to discuss Arthritis Foundation advocacy. Please keep record of all postings.

22. Choose your own! Please contact Julie Eller (jeller@arthritits.org) for activities not listed here that may count toward a bonus activity. All activities must be Arthritis Foundation advocacy related.

“Through advocacy and telling our stories, we will bring change. We need to tell our stories so our lawmakers know the challenges we face. We need to keep showing up so they don’t forget.”

– Amy Rabin, Platinum Ambassador, Pennsylvania
Junior Ambassadors

This new and exciting program gives teens 13 to 17 years old the opportunity to represent the nearly 300,000 kids in the U.S. who have arthritis and other rheumatic diseases, and raise awareness by sharing their personal arthritis story. This advocacy initiative will enable those who do not have a connection with arthritis to put a face to the disease. Junior Ambassadors will receive advocacy training, help raise awareness with policymakers about their disease, and receive our Junior Ambassador newsletter.

“I like advocating because it’s a chance for me to make a difference,” says Junior Ambassador Mason Merager. “It’s a great way to make your voice heard in such a big world.”

THE JUNIOR AMBASSADOR PROGRAM IS RIGHT FOR YOU IF YOU ARE:

- 13 to 17 years old.
- Willing to share your personal arthritis story, both in writing and in front of groups, at Arthritis Foundation programs and events, meetings with elected officials and other occasions.
- Enthusiastic and passionate about finding a cure for arthritis.
- Interested in meeting with peers virtually and receiving training from Foundation staff and volunteers.

PLEASE NOTE:

- Parents or legal guardians must give permission for participation in the program.
- This program is email-based – meaning participants will receive all program information by email. Parents must supply their email information and will be copied on all correspondence.
- Junior Ambassadors are not required to have arthritis – siblings and friends are also encouraged to join.

WHAT TYPES OF ACTIVITIES WILL I BE ASKED TO COMPLETE?

- Writing a letter to your elected official telling your arthritis story.
- Meeting with your elected official in his/her local congressional office.
- Telling your arthritis story at a Foundation event.
- Helping recruit Advocates at events like Walk to Cure Arthritis or Jingle Bell Run.
- Recruiting adults you know to become Advocates, like your pediatric rheumatologist and other health care providers.
- Attending a town hall meeting with your parent/caregiver.
- Finding a way to tell your arthritis story (or do research on kids with arthritis) through one of your existing activities, like school projects.
- Brainstorming other meaningful ways for Junior Ambassadors to get involved with the Arthritis Foundation.

I’M INTERESTED! HOW DO I GET STARTED IN THE JUNIOR AMBASSADOR PROGRAM?

- Complete the Junior Ambassador Application. Submission instructions are included.
- Write your arthritis story and send it to us by U.S. mail, or email your application and photo. A parent or guardian must sign the application.
- Once your completed application has been received, we will send you a letter confirming your participation.
- Participation in the program is through email. Participants and their parents must have an email account.

Send application, photo and arthritis story to:
Arthritis Foundation Junior Ambassador Program
Attn: Julie Eller, Manager of Grassroots Advocacy
1615 L St., NW, Suite 320, Washington, DC 20036
jeller@arthritis.org
“The magnitude of arthritis is misunderstood by many, so the challenge and the reward of advocacy is talking to legislators and others about how complex the disease is and watching them turn into Champions of Yes for their constituents with arthritis.”

– Anna Hyde - Vice President, Advocacy and Access
Federal

Arthritis affects more than 54 million adults and nearly 300,000 kids in the U.S. It’s the nation’s leading cause of disability. Such a widespread problem demands federal attention. Use this section as a guide to advocating for change on a national level.
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 VOTED ON.
In the U.S. House, the bill passes with a simple majority (218 of 435) as well as in the U.S. Senate (51 of 100).

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

THE BILL GOES TO THE PRESIDENT.
The president must sign the bill into law.

THE BILL IS REFERRED TO COMMITTEE(S).
The committee members analyze and mark up the bill before it can be sent to the House or Senate floor.

THE BILL IS DEBATED.
Members of Congress discuss why they support or oppose the bill.
Arthritis Foundation Federal Legislative Agenda

Arthritis is a chronic, complex disease that often requires a lifetime of tailored treatment to manage. Access to providers and treatments is a necessity for people with arthritis. Scientific research is crucial to better understanding the disease and developing improved diagnostics and treatments – and ultimately finding a cure. We surveyed our Advocates and Ambassadors to learn about the biggest challenges they face. These responses directly shaped our 2018 federal Advocacy and Access priorities. Read on to learn about these legislative opportunities for Congress.

ADDRESS HEALTH CARE REFORM: Ensure the voice of the arthritis community is heard during ongoing health care reform discussions. With your input, earlier this year we established seven legislative principles for patient-centered health care reform. The principles and other resources on health reform are available here.

RAISE VISIBILITY OF ARTHRITIS WITH POLICYMAKERS: Work with the administration and federal agencies on key issues affecting people with arthritis including chronic pain, disability, and mental health.

REDUCE BARRIERS TO PATIENT ACCESS: Advocate for patient access to care and ensure that timely, continuous, and affordable access to health care for people with chronic disease is a priority. Key legislation that addresses these barriers includes:
- H.R. 2999, the Patients’ Access to Treatments Act, which would cap out of pocket costs for specialty tier drugs.
- H.R. 2077, the Restoring the Patient’s Voice Act, which would restrict the inappropriate use of step therapy protocols (H.R. 2077, the Restoring the Patient’s Voice Act). Check out our coalition letter on H.R. 2077 to learn more about the bill.

INCREASE FUNDING FOR ARTHRITIS RESEARCH: Grow vital arthritis research programs at the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health, and create an arthritis research program at the Department of Defense. The CDC Arthritis Program is the only federal program dedicated solely to helping people with arthritis and only has enough funds to offer state grants to 12 states. We continue to urge Congress to increase funding by $5 million, bringing the total to $16 million. Read more here.

In addition, it is vital that funding is increased for research at the National Institutes of Health, particularly the National Institute for Arthritis, Musculoskeletal, and Skin Diseases. The establishment of a dedicated arthritis research program at the Department of Defense is equally critical for the one in three veterans that has doctor-diagnosed arthritis.

REDUCE HEALTH CARE PROVIDER WORKFORCE SHORTAGES: Help to strengthen the provider workforce by working toward passage of the Ensuring Children’s Access to Specialty Care Act (S. 989 / H.R. 3767). Nearly 300,000 children in the U.S. have arthritis, yet there are fewer than 350 practicing pediatric rheumatologists in the country, mainly clustered in big cities. This means only a quarter of children with arthritis have convenient access to a pediatric rheumatologist, the type of specialist best suited to treat their disease.

ADDRESS CHALLENGES WITH CHRONIC PAIN: Increase awareness and ease the burden of the overwhelming challenges people with arthritis face in managing chronic pain. Learn more about breaking the arthritis pain chain here.

GROW THE CONGRESSIONAL ARTHRITIS CAUCUS: Work with the Caucus to address the most pressing issues facing people with arthritis. Chaired by Reps. Anna G. Eshoo (D-CA) and David B. McKinley (R-WV), the Congressional Arthritis Caucus is a clearinghouse for information and a bipartisan forum to educate members about arthritis.
Join the Congressional Arthritis Caucus

Awareness is one of the major roadblocks in conquering arthritis. We want to build a stronger Congressional Arthritis Caucus to help educate all members of Congress about how arthritis impacts their communities and how to help support federal and local initiatives that address improved access to care. As an Advocate, you can contact your elected officials in the United States Congress and encourage them to join the Congressional Arthritis Caucus!

Why Join the Congressional Arthritis Caucus?

- **BECAUSE ARTHRITIS IS OUR NATION’S LEADING CAUSE OF DISABILITY**, resulting in an annual $304 billion price tag from direct (medical) and indirect (lost earnings) costs.
- **BECAUSE MORE THAN 50 MILLION AMERICANS HAVE ARTHRITIS TODAY**, and that number is expected to climb to 78 million by 2040.
- **BECAUSE, ACCORDING TO THE CDC, 1 IN 20 WORKING AGE ADULTS HAVE TO CHANGE JOBS**, stop working entirely, or reduce the hours they work due to arthritis.
- **BECAUSE ARTHRITIS PAIN IS A BARRIER TO THE TREATMENT OF OTHER CHRONIC DISEASES.** Anxiety and depression affect 1/3 of U.S. adults with arthritis 45 years of age or older. 47% of adults with diabetes, 49% of people with heart disease, and one third of obese adults also have arthritis.
- **BECAUSE THE IMPACT OF ARTHRITIS IS WORSE ON RACIAL AND ETHNIC MINORITY GROUPS.** 44.6% of Non-Hispanic Blacks and 43.2% of Hispanics with arthritis report activity limitation.
- **BECAUSE TOGETHER WE CAN FIGHT TO END ARTHRITIS.**

The mission of the Bicameral Congressional Arthritis Caucus, co-chaired by Reps. McKinley (R-WV) and Eshoo (D-CA), is to serve as a clearinghouse for information on arthritis and a bipartisan forum to aid members of Congress in working together to address arthritis. The caucus strives to raise awareness about arthritis and work toward educating all members about how arthritis impacts their communities and how to support federal and local initiatives addressing arthritis in all its forms. For more information about this group or to join, please contact the offices of Reps. McKinley or Eshoo.
Legislation in the Spotlight: Step Therapy

Step therapy, also known as “fail first,” jeopardizes the patient-physician relationship. It is a process that may require patients to try and fail medications chosen by the insurer, before they are able to receive the optimal treatment originally prescribed by their health care provider. In some instances, patients may need to try and fail one or more medications that are preferred by the insurer before they are able to receive the optimal treatment. In April 2017, U.S. Representatives Brad Wenstrup (R-OH) and Raul Ruiz (D-CA), both physicians, introduced the bipartisan legislation, H.R. 2077, Restoring the Patient’s Voice Act to protect the physician-patient relationship.

Here’s what H.R. 2077 does for people with arthritis:

• Restores the doctor-patient relationship by requiring employer-sponsored health plans to establish a clear and convenient process to allow physicians to request an exception to a step therapy protocol for a patient.

• Protects patients: Grants patients exceptions to step therapy protocols under five critical circumstances.

• Expedites care: Provides an exception to step therapy protocol in a timely manner - three days for a standard exception and 24 hours in a potentially life threatening situation.

Requiring patients to cycle through different treatments can take time and delay access to the right treatment. These delays can ultimately lead to disease progression. In an op-ed, Arthritis Foundation CEO Ann Palmer and the President of the American College of Rheumatology describe the challenges people with arthritis face with step therapy. A survey of more than 1,400 patients conducted in July-August 2016 by the Arthritis Foundation revealed that over half of all patients reported having to try two or more different drugs prior to getting the one their doctor had originally ordered. Step therapy was stopped in 39 percent of cases because the drugs were ineffective, and 20 percent of the time due to worsening conditions. Incredibly, nearly a quarter of patients who switched insurance providers were required to repeat step therapy with their new carrier.

Read the op-ed here.
Armed with Data: Reinforcing Your Story

Your arthritis story is important and Members of Congress listen. Reinforcing your story with data adds additional weight to your conversation with policymakers. For instance, noting the prevalence of arthritis in your state is one important data point. Check out some other critical statistics here. *Arthritis by the Numbers, State Fact Sheets.*
Leadership of the Senate and the House

We work with the key committees and leadership in Congress to help build support for initiatives and pass legislation important to people with arthritis. If your Members of Congress are represented in Congressional leadership or on any of the committees, it’s even more important to share your story! Learn more about key Senators and Representatives in Congress below. For more detailed information about the functions of the key committees, visit the Glossary.

U.S. Senate
Majority Leadership
Sen. Mitch McConnell (R-KY) Majority Leader | @McConnellPress
Sen. John Cornyn (R-TX) Majority Whip | @JohnCornyn
Sen. John Thune (R-SD) Republican Conference Chair | @SenJohnThune

Minority Leadership
Sen. Charles Schumer (D-NY) Minority Leader | @SenSchumer
Sen. Richard Durbin (D-IL) Minority Whip | @SenatorDurbin
Sen. Patty Murray (D-WA) Assistant Democratic Leader | @PattyMurray

U.S. House of Representatives
Majority Leadership
Rep. Paul D. Ryan (R-WI-01) Speaker | @SpeakerRyan
Rep. Kevin McCarthy (R-CA-23) Majority Leader | @GOPLeader
Rep. Steve Scalise (R-LA-1) Majority Whip | @GOPWhip
Rep. Cathy McMorris Rodgers (R-WA-5) Republican Conference Chair | @cathymcmorris
Rep. Luke Messer (R-IN-06) Republican Policy Committee Chair | @RepLukeMesser

Minority Leadership
Rep. Nancy Pelosi (D-CA-12) Minority Leader | @NancyPelosi
Rep. Steny Hoyer (D-MD-05) Minority Whip | @WhipHoyer
Rep. James Clyburn (D-SC-06) Assistant Democratic Leader | @Clyburn
Rep. Joseph Crowley (D-NY-14) Democratic Caucus Chairman | @repjocrowley
Key Committees

SENATE COMMITTEE ON APPROPRIATIONS
Chair: Sen. Thad Cochran (R-MS) | @SenThadCochran
Ranking Member: Sen. Patrick Leahy (D-VT) | @SenatorLeahy

SUBCOMMITTEE ON LABOR, HEALTH, HUMAN SERVICES, EDUCATION AND RELATED AGENCIES (LHHS)
Chair: Sen. Roy Blunt (R-MO) | @RoyBlunt
Ranking Member: Sen. Patty Murray (D-WA) | @PattyMurray

SUBCOMMITTEE ON DEFENSE
Chair: Sen. Thad Cochran (R-MS) | @SenThadCochran
Ranking Member: Sen. Richard Durbin (D-IL) | @SenatorDurban

SENATE BUDGET COMMITTEE
Chair: Sen. Michael Enzi (R-WY) | @SenatorEnzi
Ranking Member: Sen. Bernie Sanders (D-VT) | @SenSanders

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

HOUSE COMMITTEE ON APPROPRIATIONS
Chair: Rep. Rodney P. Frelinghuysen (R-NJ-11) | @USRepRodney
Ranking Member: Rep. Nita Lowey (D-NY-17) | @NitaLowey

SUBCOMMITTEE ON LABOR, HEALTH, HUMAN SERVICES, EDUCATION AND RELATED SERVICES (LHHS)
Chair: Rep. Tom Cole (R-OK-04) | @TomColeOK04
Ranking Member: Rep. Rosa DeLauro (D-CT-03) | @rosadelphia

SUBCOMMITTEE ON DEFENSE
Chair: Rep. Kay Granger (R-TX-12) | @RepKayGranger
Ranking Member: Rep. Pete Visclosky (D-IN-01) | @RepVisclosky
Key Executive Branch Departments and Agencies We Engage

While the legislative branch makes the laws, the executive branch is charged with implementing them. Read on to learn more about the key departments that we engage to ensure laws and regulations impacting people with arthritis are implemented appropriately.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC works to protect America from health, safety and security threats. 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. As our health protection agency, the CDC saves lives and protects people from health threats. To accomplish its 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)

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

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 in 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 food on Americans’ shelves safe and infectious diseases at bay, and by pushing the boundaries of how we diagnose and treat disease.

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 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 speed up product innovations.

FDA PATIENT ENGAGEMENT COLLABORATIVE

The FDA is committed to collaborating with patients, caregivers, and advocates, as well as incorporating the various perspectives from these groups into the FDA’s regulatory decision-making processes. The PEC will provide an ongoing forum to discuss how to achieve more meaningful patient engagement in medical product development and other regulatory discussions. Topics to be discussed may include making patient engagement more systematic; how to improve transparency, education and communication; new strategies for enhancing patient engagement; and new models for patients to collaborate as partners in the medical product development and FDA review process.
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 2016, and disability in people over age 65 has dropped dramatically in the past three decades.
State

Much like the federal government, advocacy at the state level requires Advocates like you to share their story with elected officials. Here you’ll learn about some of our legislative victories and the positions we take on issues the arthritis community faces.
State Victories

Our Army of Advocates have increased access to care for more than 52 million people by helping to enact 77 new laws in 42 states since 2014.
Story Banking Project

The best way for us to take action and help tackle access to care issues is to let your stories power our priorities. When you experience a barrier to care like Step Therapy or a Prior Authorization protocol, we want to hear about it. You can share your stories with our team on our website. Your story may be used in upcoming testimonies, letters for publication, and other platforms. We will notify you when such opportunities arise. Our team may reach out to you to learn more about your experiences and connect you directly with local opportunities. You can be the voice for people with arthritis.
State Fact Sheet Toolkit

Our State Fact Sheets can be used as leave-behind documents in meetings with legislators. They are located within the Tools & Resources section of our website and are ready to use when you’re ready.
Position Statements

Ignoring the pain and disability of arthritis is unacceptable. By pushing for policies and laws that protect patients and make health care more accessible, we will conquer this debilitating disease and make a positive impact on the lives of people with arthritis.

Expanding our state advocacy is an important piece of moving the needle. Read on to see how we plan to expand advocacy in states and our positions on state legislation.

[Here we’d like to use the graphic from our 2018 Priorities document, but it would be nice if this wasn’t just a screen shot. Can we use the graphic elements from that piece and drop them in here?]

**REDUCE BARRIERS TO PATIENT ACCESS:**
- Limit the use of step therapy, which can restrict access to needed therapies for patients.
- Ensure patients and providers are notified when an interchangeable biosimilar substitution is made.
- Streamline prior authorization protocols to limit lengthy delays and frustrations to doctors, patients, and pharmacies.
- Tackle high out-of-pocket costs for specialty medications.
- Prohibit inappropriate formulary changes, which can negatively impact a stable patient’s ability to remain on therapy.

**PROMOTE PATIENT PROTECTIONS ONCE LEGISLATIVE VICTORIES BECOME LAW:** As legislative changes become law, we will educate the arthritis community about new patient protections in their states.

**CONNECT ADVOCATES WITH OPPORTUNITIES TO ENGAGE LOCALLY**

**ENGAGE OUR NETWORK OF STATE ADVOCACY COMMITTEES:** Active volunteers will help broaden our reach and visibility.

**REFORM STEP THERAPY**
- Step therapy is an insurance practice that requires patients to use a lower-cost drug before permitting more expensive drugs – regardless of what your doctor prescribed. This may occur even if you are already taking that pricier medication and doing well on it.
- **TAKING ACTION:** Legislation to address this practice ensures step therapy protocols are based on clinical guidelines and not solely cost, requires that appeals be determined within 72 hours for non-emergency and 24 hours for emergency cases, and establishes circumstances for physicians to override step therapy when medically appropriate.

**ACCESS TO BIOSIMILARS**
- Biologic medications are life-changing for many people with inflammatory forms of arthritis. “Biosimilars” – not quite exact copies of brand-name biologic drugs – are expected to make these types of drugs more affordable and accessible to more patients. The FDA has approved several biosimilars for arthritis, but requires a higher level of similarity for these drugs to be considered “interchangeable” and therefore be eligible for automatic substitution by a pharmacist.
- **TAKING ACTION:** Advocacy efforts are aimed at ensuring biosimilars can be substituted safely and that the patient and physician are informed of – and can override – the substitution of a biologic with a biosimilar.
PRIOR AUTHORIZATION
- Many insurers require prior approval before giving you the OK to get an expensive drug.
- This process can be long and cumbersome, and often creates a significant administrative burden for both patients and providers. Further, it can keep patients from accessing the drugs they need to remain healthy.
- **TAKING ACTION:** The Foundation backs measures to streamline the prior authorization process and to require the insurer to respond within 48 hours.

OUT OF POCKET COSTS
- Insurers often place expensive drugs like biologics on specialty tiers, requiring you to pay a percentage of the cost (sometimes as much as 50 percent) rather than a fixed-dollar copay.
- This can cause a patient to reach their annual out-of-pocket spending cap in the first few months of the plan year, a significant financial burden for many patients.
- **TAKING ACTION:** Some new state laws rein in out-of-pocket expenses by limiting the cost of a 30-day prescription, limiting a patient’s total monthly prescription costs, and making sure they can get in-network services.
- Some laws also require a certain percentage of plans to offer co-pays instead of more costly co-insurance requirements.
- Other proposals would let patients spread out payments on their deductible so they don't face the full cost of their deductible in the first months of their plan year.

MID-YEAR FORMULARY CHANGES
- When selecting a health insurance plan, many people with chronic conditions make their decision after carefully weighing a complex variety of factors, including plan cost, medication formulary costs, cost sharing, the availability of specialists and the choice of hospitals.
- Insurance companies can change the available benefits of a policy during a contract year, negatively impacting the insured.
- These changes could involve removing a drug from coverage altogether or moving a drug to a higher cost-sharing tier.
- **TAKING ACTION:** The Foundation supports legislation that would prohibit insurers from making negative formulary changes during the middle of a contract year.

INSURANCE PLAN TRANSPARENCY
- Before committing to an insurance plan, you can go to the insurer’s website and compare the costs and benefits, but you can’t always get important details, like coverage of specific medications, what you’ll pay out of pocket or whether the insurer will make you first try cheaper medications (step therapy).
- **TAKING ACTION:** New legislation and regulations can ensure that insurance plans are clear and understandable, so consumers can find out whether their medications are covered, how much they will have to pay, and whether there are special requirements, such as prior authorization by the insurer or step therapy.

PROMOTE PATIENT PROTECTIONS ONCE VICTORIES BECOME LAW
Remember that we are on your team and will stand with you; whether you are facing a barrier to care, fighting for introduction of a new bill, or celebrating the passage of a bill into law.

We are here to be a resource to ensure that your new protections are implemented fully and that patients in your state know their new patient rights. We are your training source: hosting webinars, providing you with resources, and ensuring the new laws in your state are enforced appropriately.
CONNECT ADVOCATES AND AMBASSADORS WITH WAYS TO ENGAGE LOCALLY

Your priorities inform our mission. Your feedback through surveys, focus groups, webinars, and more directly inform the scope of our work!

An additional way that we engage locally is through our state advocacy committees. Committee members:

- Identify opportunities to recruit, train and cultivate Advocates and Ambassadors.
- Monitor barriers to access to safe, affordable treatments across all platforms on the state/local level.
- Serve as voice of arthritis patients in pursuing state/local legislators and policy makers.
State Implementation Efforts

As our legislative wins become realities, the Arthritis Foundation is your go-to resource to ensure that your new protections are implemented fully and that patients in your state know their new patient rights. Specifically in 2018, we will be focusing our implementation efforts on step therapy, prior authorization and out of pocket laws. We will be your training source: hosting webinars, providing you with resources, and ensuring the new laws in your state are enforced appropriately.

• During our webinars, advocates will have the opportunity to hear from experts and ask questions.

• In 2017, the Arthritis Foundation partnered with the Ohio State Medical Association on a Prior Authorization webinar. During the webinar we discussed the new protections for Ohioans facing prior authorization. Megan Faust, 2017 Platinum Ambassador and JA mom shares her family’s experience with prior authorization. Tim Maglione, of the Ohio State Medical Association then takes a deep dive into the new law’s implementation and what patients should expect.

• We will continue to publish blog posts and emails on all of our victories – and will add to this effort by sharing educational resources on new patient protections and what they mean to patients and providers.

• Lastly, we will ensure that the new laws in your state are enforced appropriately by continuing outreach to State Insurance Commissioners. If you are experiencing barriers to your health care, make sure to inform your State Insurance Commissioner. This resource: http://coveragerights.org/ allows you to easily find instructions on how to appeal, request an external review, or file a complaint. The map allows you to find the appropriate process for your state and the contact information for your Department of Insurance.
Find Your Elected Officials

Visit the Action Center on our website to find your locally elected officials.

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 Association of Insurance Commissioners
State Insurance Commissioners who will help to ensure that the new laws in your state are enforced appropriately. If you are experiencing barriers to your health care, make sure to inform your State Insurance Commissioner. For more information, go to coveragerights.org
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 arthritis.org/advocacy

#AdvocateforArthritis
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.

Anna Hyde,
Vice President, Advocacy and Access
Arthritis Foundation
We hope you find these tools helpful. They are building blocks to support your advocacy work – because you are the most important part of the movement to cure arthritis. We believe you possess the ability to make 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 the health care system, had your letter to the editor published or formed a relationship with an important policymaker, we want to hear about it. Tell us by sending your story to advocacy@arthritis.org. 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 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.
ACT: Legislation (a bill or joint resolution) that has passed both chambers of Congress (or a state legislature) in identical form, been signed into law by the president (or the governor), or pass over his/her veto, thus becoming law.

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

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

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

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

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

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

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

CLOTURE: The method by which a supermajority (typically, three-fifths) of the U.S. Senate may agree to limit further debate and consideration of a question (e.g., a bill, amendment or other matters).
**COMMENT LETTER:** A formal letter to a federal or state agency commenting on a proposed or final rule or regulation. It is our formal opportunity to publicly state our views on an agency rule.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

These definitions are drawn from the Library of Congress or U.S. Senate glossaries.
Glossary | Leadership Senate and House

**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 legislation that allocates federal funds to numerous government agencies, departments and organizations on an annual basis. Appropriations are limited to the levels set by a budget resolution, drafted by the Senate Budget Committee. There are 12 subcommittees tasked with drafting legislation to allocate funds to government agencies within their jurisdictions.

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

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

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

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

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

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

**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.

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

**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).

**HOUSE COMMITTEE ON ENERGY AND COMMERCE:** The House Committee on Energy and Commerce is vested with the broadest jurisdiction of the Congressional committees with responsibility over a broad portfolio of topics like consumer protection, food and drug safety, and public health research, environmental quality, and interstate and foreign commerce. It also oversees multiple cabinet-level departments and independent agencies, including the Department of Health and Human Services, and the Food and Drug Administration.
**SUBCOMMITTEE ON HEALTH:** This subcommittee has jurisdiction over public health and quarantine; hospital construction; mental health; biomedical research and development; health information technology, privacy and cybersecurity; public health insurance (Medicare, Medicaid) and private insurance; medical malpractice and medical malpractice insurance; the regulation of foods, drugs and cosmetics; drug abuse; the Department of Health and Human Services; the National Institutes of Health; the Centers for Disease Control and Prevention; Indian Health Service; and all aspects of the above referenced jurisdiction related to the Department of Homeland Security.

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

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

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

Glossary | Coalitions