

Conclusion

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

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



Sandie Preiss
National 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.

Federal Coalitions

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

Ad Hoc Group for Medical Research

Network of groups interested in medical research; holds periodic town halls to discuss issues and strategy. Advocates for top-line NIH funding.

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

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

Coalition for Accessible Treatments

Coalition created by the Arthritis Foundation and the American College of Rheumatology to advocate for affordable patient out-of-pocket costs for medications. The Arthritis Foundation is a steering committee member.

Coalition for Clinical Trials Awareness

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

Coalition for Health Funding

Largest coalition dedicated to public health funding with over 90 members. Advocates for top-line funding of HHS agencies; also heavily involved in sequestration and broader budget issues.

Friends of Centers for Disease Control and Prevention

Advocates for top-line CDC funding and meets annually.

Friends of the Congressional Arthritis Caucus

Coalition dedicated to enhancing the visibility of arthritis issues on Capitol Hill and growing the Congressional Arthritis Caucus.

Friends of Health Resources and Services Administration (HRSA)

Advocates for top-line HRSA funding, holds annual meeting with the HRSA director and staff every year, and sends updates on HRSA funding bills and news.

Friends of VA (Department of Veterans Affairs) Medical Care and Health Research

Coalition dedicated to strong funding for VA research and health programs.

Graduate Medical Education (GME) Coalition

Coalition led by the Association of American Medical Colleges that advocates for raising or eliminating the caps on federally-funded medical residency slots, graduate medical education reform and increasing resources for graduate medical education.

Healthcare Leaders for Accountable Innovation in Medicare

Coalition focused on adding the patient voice to cost-saving innovations in the Medicare program. The Arthritis Foundation is a steering committee member.

MAPRx Coalition

Coalition that advocates for Medicare Part D and considers a variety of issues, including benefit design, premiums and medication therapy management.

Medicare Therapy Cap Coalition

Coalition dedicated to repealing the Medicare cap on physical therapy.

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

Advocates on behalf of NIAMS; holds meetings with NIAMS staff; conducts a biannual site tour for Capitol Hill staff and a biannual outreach and education day for coalition members; holds briefings and other events on the Hill each year. The Arthritis Foundation is a steering committee member.

National Coalition of Autoimmune Patient Groups

Coalition of autoimmune groups that advocates for a variety of issues, including specialty drugs, research funding and access to providers and treatment.

Patients for Biologic Safety and Access

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

Pediatric Subspecialty Workforce Coalition

Coalition advocating for pediatric subspecialty eligibility in federal loan repayment programs.

Regulatory Education and Action for Patients (REAP) Coalition

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

Rx For US

Coalition led by the National Association of Chain Drug Stores that advocates for patient access to medications and medication therapy management legislation.

State Legislative Coalitions

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

Cap the CoPay

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

Coalition Against Switching Medications for Stable Patients

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

State Access to Innovative Medicines (State-AIM)

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

Glossary

Glossary | Policy & Advocacy

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

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

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

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

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

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

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

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

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

COMMENT LETTER: A formal letter to a federal 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.

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 | 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)