INTRODUCTION

Welcome to the Platinum Ambassador Assembly 2018! This first-of-its-kind event will focus on precision advocacy, helping you cultivate the skills to take your advocacy to the next level on Capitol Hill and in your local communities. Over 100 of the Arthritis Foundation’s most highly engaged volunteers are traveling to the nation’s capital to #AdvocateForArthritis. In addition to sessions designed to enhance your advocacy through state advocacy committees and fundraising, you will be taking some key health care issues to Capitol Hill and sharing your story with your members of Congress. Together we will urge Congress to make step therapy processes more transparent for patients, spread the word about the benefits of joining the Congressional Arthritis Caucus, and ensure people with arthritis have access to affordable, quality care.

As part of our precision advocacy focus, we will be giving you a menu of legislative asks to choose from for your Hill visits. Our core asks will be around step therapy legislation and the Arthritis Caucus, and the menu of options will include policies on a range of topics, from pediatric rheumatology shortages to out-of-pocket costs. Read on for issue briefs on each of these issues.

TOP ISSUES

Each group will take our two core asks into their meetings, and will choose one additional ask from the menu.

Core Asks

- Restoring the Patient’s Voice Act (H.R. 2077)
- Bipartisan Congressional Arthritis Caucus

Menu (Choose One)

1. Ensuring Children’s Access to Specialty Care Act (H.R. 3767 / S. 989)
2. Patients’ Access to Treatments Act (H.R. 2999)
3. Arthritis Research at the Department of Defense
4. Arthritis Public Health Programs – Centers for Disease Control and Prevention
5. Enhanced Flexibility of Health Savings Accounts (HSAs)
6. Capping Out-of-Pocket Costs in Medicare (S. 1347)
CORE // REFORMS TO STEP THERAPY

BACKGROUND
Step therapy – also known as “fail first” – is a practice employed by many insurers that requires patients to try lower-cost therapies before being approved for the therapy their doctor prescribed – even when doctors are certain that the cheaper option won’t be effective. When inappropriately used, step therapy can undermine the clinical judgment of health care providers and put patients’ health at unnecessary risk. Many patients must try multiple drugs before finding one that works for them, so the ability to remain on a drug that works is critical.

The real problems that step therapy can cause patients were illustrated in a 2016 survey by the Arthritis Foundation:
- Over 50% 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% of cases because the drugs were ineffective, and 20% of the time due to worsening conditions; and
- Nearly 25% of patients who switched insurance providers were required to repeat step therapy with their new carrier.
- Most respondents experienced negative health effects from delays in getting on the right treatment.

WHAT CONGRESS CAN DO
There is a simple and straightforward way to fix the step therapy process: Congress can pass H.R. 2077, the Restoring the Patient’s Voice Act. The legislation is sponsored by two physicians in Congress – Reps. Brad Wenstrup (R-OH) and Raul Ruiz (D-CA) – who have encountered step therapy in their own practice of medicine. The bill also has nearly 40 bipartisan co-sponsors. There is currently no companion bill in the U.S. Senate.

The bill creates a new opportunity for patients with employer-sponsored insurance by:
- Calling for a clear and transparent process to seek exceptions to step therapy review by health insurance plans;
- Establishing a reasonable and clear timeframe for override decisions; and
- Requiring insurers to consider the patient’s medical history, the provider’s expertise in partnership with their own patient, and respect the health care provider’s professional judgment – before a health plan can delay or outright deny a patient’s ability to access a medically necessary treatment.
CORE // JOIN THE ARTHRITIS CAUCUS

BACKGROUND
Arthritis is our nation’s leading cause of disability, resulting in an annual $300 billion economic burden from direct (medical) and indirect (lost earnings) costs.

More than 54 million Americans have arthritis now, and that number is expected to climb to 78 million by 2040. Further, arthritis limits the daily activities of nearly 23 million Americans. There is a strong need for Congress to address this growing problem.

The mission of the bicameral Congressional Arthritis Caucus is three-fold:
• Serve as a clearinghouse for information on arthritis and a bipartisan forum to aid members of Congress in working together to address arthritis;
• Raise awareness about arthritis and work toward the goal of educating all members of Congress about how arthritis impacts their communities and constituents; and
• Offer ways for members of Congress to help support federal and local efforts addressing arthritis in all its forms.

WHAT CONGRESS CAN DO
Join the Congressional Arthritis Caucus! Awareness is one of the major roadblocks in conquering arthritis. We want to build a strong Congressional Arthritis Caucus to highlight:
• The scope of arthritis and other rheumatic diseases;
• The current shortage of rheumatologists and pediatric rheumatologists; and
• The importance of biomedical research to unlock new treatments and cures.

The caucus is chaired by Reps. Anna Eshoo (D-CA) and David McKinley (R-WV). Nearly 150 members of Congress have already joined the bipartisan Caucus.

“Arthritis is not a Republican or a Democratic disease,” caucus co-chair Rep. Eshoo has said. “Chronic diseases bear none of those labels...it really behooves us to work together.”
1. // ENSURE ACCESS TO PEDIATRIC RHEUMATOLOGISTS

BACKGROUND
There is a severe shortage of pediatric rheumatologists in the United States, with fewer than 350 board-certified, practicing pediatric rheumatologists, primarily clustered in and around large cities. Startlingly, 8 states have no pediatric rheumatologist and 5 states have only one. As a result, the over 300,000 patients with juvenile rheumatic diseases have limited access to the care and treatment they need:

- Only 25% of children with arthritis are currently able to see a pediatric rheumatologist;
- The workforce is aging, with the average pediatric rheumatologist in his or her early-to-mid 50s;
- A child with rheumatic disease must travel an average of 57 miles to be seen by a pediatric rheumatologist – more than double the average number of miles for other pediatric subspecialties.

Access to pediatric rheumatologists is important for a variety of reasons:

- Early diagnosis/treatment is critical for disease management, and it can be difficult for providers untrained in pediatric rheumatology to diagnose arthritis.
- Pediatricians tend not to be adequately trained to care for children with juvenile arthritis, while adult rheumatologists are not trained to deal with pediatric issues – whether it be the stunted bone growth that can result from arthritis and its treatment, or the special requirements of providing treatment to an adolescent.
- Treatment of arthritis is complex and there are many potential co-morbidities and related diseases, such as uveitis and TMJ disorders.
- Access to a pediatric rheumatologist increases access to novel therapies, including therapies that are only available in clinical trials.

WHAT CONGRESS CAN DO
Loan repayment and scholarship programs can help incentivize physicians to practice in rural and under-served areas and specialize in pediatric rheumatology. Members of Congress can co-sponsor S. 989/ H.R. 3767, the Ensuring Children’s Access to Specialty Care Act, introduced by Senators Roy Blunt (R-MO) and Jack Reed (D-RI) in the U.S. Senate, and Representatives Billy Long (R-MO) and Joe Courtney (D-CT) in the House of Representatives.

This bipartisan legislation would make pediatric subspecialists like pediatric rheumatologists eligible for the National Health Service Corps (NHSC) and help ensure children in areas with shortages have access to providers best suited for their needs.

The bill is supported by more than 40 national organizations, including the Arthritis Foundation, the American Academy of Pediatrics, and the American Academy of Child and Adolescent Psychiatry, among others.
2. // LIMIT COST-SHARING FOR SPECIALTY DRUGS

BACKGROUND

An alarming trend in today’s health insurance market is the practice of moving more expensive drugs like biologics onto specialty tiers that utilize high patient cost-sharing methods like co-insurance. Specialty tiers commonly require patients to pay a percentage of the cost of the drug (co-insurance), rather than a fixed co-pay, which can range from 25 to 50 percent or higher, resulting in hundreds – and even thousands – of dollars per month in out-of-pocket costs.

While expensive, biologics are a true innovation for people with autoimmune forms of the arthritis, like rheumatoid arthritis (RA). These complex medications, made from living organisms, use the body’s immune system to fight the condition, and in some cases even halt its progression. For many patients, biologics are a game changer, but affordability of treatments is interchangeable with access to these life-changing treatments.

High costs put patient access to drugs at risk: studies show that the higher the out-of-pocket costs, the less likely patients are to take their medications on time, if at all. Failure to adhere to a treatment plan because of lack of access to medications can lead to worsening disease, increased rates of disability, loss of function, loss of productivity and independence, and rising health care costs as patients may require expensive interventions like surgery.

WHAT CONGRESS CAN DO

Members of Congress can co-sponsor H.R. 2999, the Patients’ Access to Treatments Act, which would require commercial health insurers to cap the co-payment for specialty drugs at the level for the non-preferred brand drug tier (typically Tier 3).

This bipartisan legislation is sponsored by Reps. David McKinley (R-WV) and Lois Capps (D-CA) in the House of Representatives and has 30 co-sponsors.

The Arthritis Foundation is one of 32 members of the Coalition for Accessible Treatments, a coalition that is working to ensure patients have access to treatments for lifelong, chronic diseases. The group strongly supports the bill.
3. // ARTHRITIS RESEARCH AT DEPARTMENT OF DEFENSE

BACKGROUND
One in three veterans lives with arthritis, a serious, chronic and complex disease that affects one in four Americans in the general population. Arthritis carries with it enormous physical, financial and societal costs, but for veterans and service members, the costs are multiplied. Research supporting better prevention strategies, interventions and treatments is critical to reducing the number of service members and veterans suffering from arthritis.

Why Service Members Are More Prone to Arthritis
- Service members carry 60-100+ lb. packs that can injure and weaken their joints.
- Shock waves from bomb blasts can cause early joint damage, leading to post-traumatic osteoarthritis.
- Service members injured by roadside bombs and other blasts are often diagnosed with arthritis drug within two years of being injured, versus civilian injuries where onset of arthritis usually occurs 10 years later.

What the Consequences are to Service Members and Veterans
- Osteoarthritis (OA) is the second most common reason soldiers are medically discharged from the U.S. Army.
- Service members are often injured at a young age, which translates to more years of joint-related symptoms, activity limitations and risks associated with medical procedures.
- The number of veterans with arthritis is rising, placing an increasing cost burden on the Department of Veterans Affairs (VA), a cost ultimately born by the U.S. taxpayers; between FY2009 and FY2013, more than 5.7 million veterans received disability compensation for musculoskeletal conditions.

How Further Arthritis Research Can Help
- Identify better joint injury management to reduce the effects of joint degeneration in this population.
- Identify ways to lessen joint injury during military training, which will lead to more effective treatments for all people with arthritis.
- Develop interventions at the time of injury to delay or prevent onset of arthritis.

WHAT CONGRESS CAN DO
Submit a letter of request to the Appropriations Subcommittee on Defense asking for a stand-alone arthritis program within the DoD Congressionally Directed Medical Research Program (CDMRP), funded at $20 million. Currently, arthritis and clinical care research on military personnel is limited with no dedicated funding year to year. Further, arthritis research that helps our military and veteran populations will benefit everyone with arthritis, which is the number one cause of disability in the United States.
4. // FUND ARTHRITIS PUBLIC HEALTH PROGRAMS

BACKGROUND
Beyond the important medical research into the causes of arthritis at the National Institutes of Health and Department of Defense, robust funding for arthritis-related prevention and public health programs is critical to offering evidence-based resources to people with arthritis.

The Centers for Disease Control and Prevention’s (CDC) Arthritis Program is the only federal program dedicated solely to arthritis, the nation’s leading cause of disability. As a result, the program collects data vital to understanding arthritis prevalence, trends, and factors impacting quality of life for individuals with this chronic disease. The Arthritis Program also funds states and national partners to deliver evidence-based exercise and self-management programs that have proven to decrease symptoms associated with arthritis.

The goal of the CDC’s Arthritis Program is to improve the quality of life for people affected by arthritis and other rheumatic conditions by working with states and other partners to:

- Increase awareness about appropriate arthritis self-management activities;
- Extend the reach of programs proven to improve the quality of life for people with arthritis; and
- Decrease the overall burden of arthritis as well as its associated disability, work and activity limitations.

The CDC estimates that physical activity programs can reduce annual health care costs by about $1,000 per person. Expanding the reach of the Arthritis Program can have a significant return on investment and greatly improve the lives of people suffering from arthritis.

WHAT CONGRESS CAN DO
Proven public health interventions for arthritis goes hand-in-hand with robust scientific research. We urge Congress to provide for a $5 million increase in funding in fiscal year 2019 for the CDC’s Arthritis Program, bringing total funding to $16 million. This modest increase would fund arthritis-related research and allow evidence-based programs to operate in 2 additional states.

Arthritis is an urgent public health priority, and it’s time for the federal investment to match the disease burden. Adequately funding programs that can ease, or even prevent, the physical suffering that comes with arthritis is an urgent need for millions of Americans. Congress must act swiftly to ensure that researchers have all the data and tools at their disposal to combat – and perhaps one day even cure – America’s leading cause of disability.
5. // ENHANCE FLEXIBILITY OF HSAs

BACKGROUND
Arthritis is a complex, chronic disease and the leading cause of disability in the United States. People with arthritis require lifelong care, and the disease can be difficult to treat. Further, people with arthritis face many of the biggest challenges in health care today: high out-of-pocket (OOP) costs, burdensome insurance requirements, and a lack of transparency in health coverage.

Health savings accounts (HSAs) paired with high deductible health plans (HDHP) are becoming more common across the country and many people with arthritis are now in these types of plans. Expanding the use of Health Savings Accounts (HSAs) has the potential to help patients manage their out-of-pocket costs, particularly for people who rely on expensive medications and reach their maximum out-of-pocket costs early in the plan year. The Arthritis Foundation recently conducted a focus group of arthritis patients to learn about their experiences with HSAs. Some of the key findings:

- All participants met deductibles and OOP maximums at the start of plan years.
- Most respondents felt burdened by demonstrating, through paperwork and long phone conversations, that expenses met the qualifications of the health plan.
- Many respondents reported that their HSA had resulted in limited care or an inability to access “everything they need to manage their disease.”
- When asked what services would attract people to HSAs, participants wanted to be able to contribute money in advance of the plan year, and contribute the total amount of their OOP costs so they are covering their entire expense.

WHAT CONGRESS CAN DO
Congress can take steps to provide additional flexibility for HSAs so that individuals with chronic diseases like arthritis have enough flexibility with their plan to feel confident their health care needs are met. The Arthritis Foundation recommends:

1. Allowing individuals and families to contribute more to their HSAs by increasing the annual contribution limit to the maximum sum of an annual deductible and OOP expenses permitted under an HDHP
2. Permitting the front-loading of HSA dollars, which is critical to ensuring HSAs work for people with chronic diseases like arthritis
3. Designing HSA policies in a way that makes it easier for the approval of qualified medical expenses and simpler to access HSA dollars
4. Supporting navigators or other personal support representatives who are trained to specifically help patients understand how to use HSAs.
5. Broadening qualified medical expenses to account for the fact that people with arthritis depend on a range of traditional and non-traditional health care services. As an example, pain management services like massage and yoga are not traditionally thought of as medical, but are important to disease management for people with arthritis.

#AdvocateforArthritis
BACKGROUND
Medicare is the government’s health care program for people 65 years of age or older, or younger people with disabilities. Improving care for Medicare patients with chronic diseases like arthritis is critical, particularly because arthritis prevalence increases with age – 50% of Americans over 65 have some form of arthritis. As 10,000 people age into Medicare every day, the spotlight has turned to policy solutions that can make the Medicare program work better for patients with chronic illnesses, especially when it comes to out-of-pocket spending.

Many Medicare patients access their medications through Part D, the outpatient prescription drug benefit. Since its inception in 2006, Medicare Part D has undoubtedly improved the affordability of medications for people on Medicare. But more work can be done. Unlike the Health Exchanges and commercial plans, there is no out-of-pocket spending cap in Medicare Part D. According to a recent analysis, Medicare Part D enrollees spent an average of $1,215 out-of-pocket on prescriptions filled beyond the catastrophic coverage phase, totaling $1.2 billion in aggregate in 2015. In the catastrophic phase, patients are assured a small co-insurance or co-payment for covered drugs for the rest of the year. However, one study found that 58 percent of patients taking specialty drugs for rheumatoid arthritis (RA) reached the catastrophic coverage threshold by the month of May. In other words, most RA patients in the Medicare Part D program spent nearly half the plan year in the catastrophic coverage phase – meaning that the reduced co-insurance rate in this phase of coverage (today about 5%) can translate into significant out-of-pocket costs.

WHAT CONGRESS CAN DO
Co-sponsor the Reducing Existing Costs Associated with Pharmaceuticals for Seniors Act (S. 1347, the RxCAP Act), which eliminates patient cost-sharing above the Medicare Part D annual out-of-pocket threshold. The legislation is sponsored by Senator Ron Wyden (D-OR) and there is currently no House companion bill.

The absence of a limit on out-of-pocket spending exposes patients to overly burdensome costs – especially for people with arthritis that require high-priced drugs such as biologics to treat and prevent progression of their disease.

The president’s fiscal year 2019 budget request suggests an approach to achieving this goal, by phasing down over four years what a patient pays in the catastrophic phase of the Part D benefit from 5 percent of the costs to 0 percent (no cost-sharing).