

## **State Arthritis Quality of Life Initiative & Advisory Council Issue Brief and Model Legislation**

### **The Issue**

Nearly 1 in 3 people aged 18-64 years live with arthritis, and it is a leading cause of work disability, resulting in over \$300 billion in direct and indirect expenses each year. It is imperative that arthritis be treated as the critical public health priority that it is. Arthritis is an umbrella term to describe more than 100+ types of diseases related to the bones and joints. Nearly 60 million adults and over 300,000 children have doctor-diagnosed arthritis, but studies suggest that these data points are substantially underestimated; arthritis prevalence is likely almost double these numbers. Currently, there is no disease-modifying treatment for the most prevalent form of arthritis – osteoarthritis (OA) – which presents a great unmet need for innovative treatment development and makes access to evidence-based symptom management programs that much more important. It is time for state investment to match the disease burden. Adequately funding programs that can ease or prevent the physical suffering that accompanies arthritis is a crucial need for millions of Americans.

The most common form of arthritis is osteoarthritis (OA). Other forms include gout, rheumatoid arthritis (RA), post-traumatic osteoarthritis, and juvenile arthritis (JA). Symptoms of arthritis include pain, aching, stiffness, and swelling in or around the joints. Rheumatoid arthritis and other autoimmune forms of arthritis can affect multiple organs and cause widespread symptoms.

Sixty percent of U.S. adults with arthritis are of working age (18 to 64 years). Arthritis can limit the type of work they are able to do or keep them from working at all. In fact, 8 million working-age adults report that their ability to work is limited because of their arthritis. For example, individuals with arthritis may have a difficult time climbing stairs, walking from a parking garage to their workplace, or sitting for long period of time

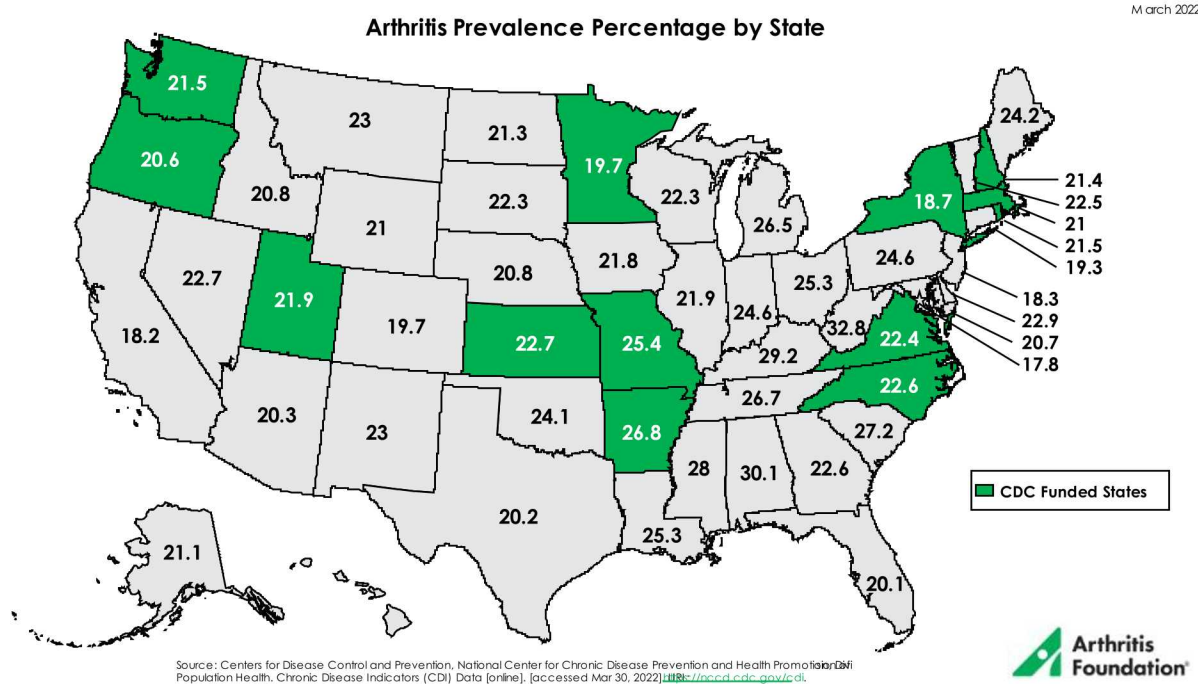
The [Arthritis Foundation's Live Yes! INSIGHTS study](#),<sup>1</sup> one of the largest patient-reported outcomes (PRO) collections of data from adults living with arthritis in the U.S., showed one thing was loud and clear: **PAIN** – the kind of pain that cannot be ignored – is the major challenge people with arthritis face daily. 100% of survey respondents reported pain over the past 7 days. The study also stated that 75% reported that pain interfered somewhat, quite a bit or very much with their day-to-day activities. 49% reported that pain interfered with their ability to fall asleep.

Without state investment in arthritis, funding is solely provided by the U.S. Centers for Disease Control and Prevention (CDC) to provide inadequate levels of aid to a limited amount of states. To manage their arthritis symptoms, ensure those with arthritis can work and do other daily activities, have less pain, manage their own care, and prevent or delay disability, the CDC conducts research and supports programs for people with arthritis. Figure 1 shows a map of the most recent CDC-funded states and the percentage of patients that have doctor-diagnosed arthritis in each state.

The CDC Arthritis Program is the only federal program dedicated solely to arthritis, yet it only receives \$11 million in annual funding, severely limiting its ability to fully reach its goals. The program plays a significant role in our understanding of the disease by collecting data vital to understanding arthritis prevalence, trends, and factors impacting quality of life. Nowhere else across the federal government is this type of public health research and data collection completed. **The need for the program is greater than ever: 78 million Americans will have arthritis by 2040.**

<sup>1</sup> <https://www.arthritis.org/getmedia/34e83e02-8932-47ce-8225-20c62bbfb52b/How-It-Hurts-Report.pdf>

FIGURE 1: Arthritis Prevalence Among Adults Aged 18 Years + in the States and CDC-funded Arthritis Program States (% based upon state population) <sup>2</sup>



In recent years, efforts to reduce health disparities and improve health equity has emerged in health policy, and states are taking action. While arthritis can impact anyone, regardless of age, gender, race or socioeconomic status, research indicates that several population groups are disproportionately affected by arthritis-related limitations: African American/Black individuals, Hispanic/Latinx American individuals, Asian American individuals, low-income individuals, and those living in rural areas. Arthritis may diminish the ability to work and participate in Activities of Daily Living, an issue compounded by systemic barriers to accessing diagnosis, treatment, and support particularly in underserved populations. These populations also disproportionately battle other chronic conditions, such as diabetes, heart disease, and anxiety, which can further exacerbate arthritis symptoms. As states act to address health equity issues, arthritis solutions should also be intertwined.

Since 2020, the COVID-19 virus has affected people with arthritis profoundly. Many patients with inflammatory type of arthritis, such as rheumatoid arthritis, take immunosuppressive medications to treat their arthritis. Throughout the pandemic, we found that the risk for complications and for severe disease outcomes and increased likelihood of hospitalization are higher among rheumatology patients.<sup>3</sup> Worried about their

<sup>2</sup> Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Chronic Disease Indicators (CDI) Data [online]. [accessed Mar 30, 2022]. URL: <https://nccd.cdc.gov/cdi>

<sup>3</sup> <https://www.arthritis.org/health-wellness/about-arthritis/related-conditions/other-diseases/covid-19-faqs-infection-risk-and-prevention>



immunity already being compromised, many arthritis patients faced increased risk and anxiety throughout the year as their social and emotional well-being were dramatically impacted. On the upside, COVID-19 brought more attention to what immunocompromised patients deal with every day. For those immunocompromised patients as well as patients with OA, they have seen their treatment options lessen during the pandemic. As states look to invest in funding to build up state public health departments to battle COVID-19 and future pandemics, overarching investment, such as funding to help those with autoimmune arthritis, within those public health departments is also critically necessary.

### **The Solution**

The funding and implementation of state arthritis programs is derived from the goals outlined in the [Arthritis Foundation's Organizational Position Statement on Pain Management](#).<sup>4</sup> The establishment of state arthritis programs will assist the CDC Arthritis Program effectively fulfill their duties to collect data vital to understanding arthritis prevalence, trends, and factors impacting quality of life. State-based officials are perfect partners to ensure that state-level information is accurate, updated in a timely manner, and interoperable with CDC's systems. The ability to have timely data will help to provide policy makers and stakeholders with the appropriate information to make educated decisions on behalf of arthritis patients in the state.

The below model language allows states to invest in arthritis patients. The three elements of the model language include: 1) Arthritis Quality of Life Initiative; 2) Advisory Council on Arthritis; and 3) Arthritis Research Program.

Without CDC funding, most states do not have a dedicated arthritis program or division within the state Department of Health and Human Services (or equivalent department). Undoubtedly, further commitment by Congress to increase funding for the CDC Arthritis Program will be important to ensure more states can implement state arthritis programs. However, states should not solely wait or depend on the CDC for this funding. State funding of state arthritis programs will send a message to arthritis patient throughout your state that your state is ready to combat the nation's leading cause of disability. Accordingly, state investments will lead to increased patient ability to participate in the workforce.

The Arthritis Foundation asserts that establishment of a state arthritis program will improve the quality of life for people affected by arthritis. The goals within these programs should include:

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

The Arthritis Foundation recommends following existing CDC guidance on several proven approaches for patients to reduce arthritis pain:

- Join a self-management, evidence-based education program, such as the Chronic Disease Self-Management Program, that teaches the skills and confidence to live well with arthritis every day.
- Be active. Physical activity—such as walking, bicycling, and swimming—decreases arthritis pain and improves function, mood, and quality of life. Adults with arthritis should move more and sit less throughout the day. Getting at least 150 minutes of moderate-intensity physical activity each week is recommended. However, any physical activity is better than none. CDC-recommended physical activity programs can improve health for participants with arthritis.
- Maintain a healthy weight. People can reduce their risk of knee osteoarthritis by controlling their weight.

<sup>4</sup> <https://www.arthritis.org/about-us/news-and-updates/arthritis-foundation-organizational-statement-on-p>

- Protect your joints. People can help prevent osteoarthritis by avoiding activities that are more likely to cause joint injuries.
- Talk with a doctor. Recommendations from health care providers can motivate people to be physically active and join a self-management education program. People with inflammatory arthritis, such as rheumatoid arthritis, have a better quality of life if they are diagnosed early, receive treatment, and learn how to manage their condition

Currently, only thirteen states can receive CDC funding to expand the reach of proven arthritis self-management education and physical activity programs and sustain them over time. States also use CDC funding to increase health care provider counseling about the benefits of physical activity for arthritis management, promote walking, and encourage referral of patients with arthritis to proven intervention programs.

CDC also works with national organizations to expand the use of these proven interventions for adults with arthritis. For example, the National Recreation and Park Association has offered support to at least 240 local park agencies in 48 states and American Samoa to deliver the Arthritis Foundation Exercise Program, Active Living Every Day, Fit & Strong!, or Walk With Ease Program. State arthritis programs would be able to build upon these already established partnerships while also creating state and local partnerships that are appropriate for that particular state.

State investment in arthritis research to compliment funding sources on a federal level is extremely important. Dedicating state funds allocated to either academic or nonacademic researchers guarantees that your state is at the forefront of advances in a space that desperately needs them. State level control also ensures that arthritis patients in your state would be the first to benefit from the investment.

Lastly, the Arthritis Quality of Life Initiative & Advisory Council is a public policy initiative that can partner with other public health focuses a state might be pursuing within chronic disease management, pain management, and other disease specific initiatives.

### **Fiscal Impact Arthritis Quality of Life Initiative & Advisory Council**

The great success seen across the country on Rare Disease Advisory Councils (RDAC) has provided detailed information regarding funding and implementation of an advisory council such as the one suggested for arthritis. Each Rare Disease Advisory Council is different in each state, so each has had a different fiscal impact to the state. Most RDAC fiscal notes ranged from \$42,000 to \$678,000 annually.

- **California:** \$678,000 - Annual expenses are estimated to be \$678,000 for staffing, operating expenses, travel and per diem (General Fund).
- **Florida:** DOH may experience an indeterminate negative fiscal impact from CS/CS/SB 272 due to the requirement that the DOH provide staff and administrative support to the Council.
- **Virginia:** \$42,716 - VDH would need a part-time contracted staff person to lead, organize, implement, and staff the Advisory Council as well as to draft and submit the annual report. VDH has estimated that the cost of the part-time contractor would be \$42,716.
- **Maine:** \$185,075 - Department of Health and Human Services will require General Fund appropriations of \$185,075 in fiscal year 2021-22 and \$103,574 in fiscal year 2022-23 for 0.5 Public Health Educator III position to coordinate all the duties associated with the Rare Disease Advisory Council and for the development and on-going costs associated with a rare disease registry. \*This bill was not enacted in the 2021 legislative session\*
- **Michigan:** \$100,000 - Fiscal cost implications of approximately \$100,000 to \$200,000 annually for DHHS. The bill requires DHHS to establish and support a new Rare Disease Advisory Council, with responsibility to investigate rare disease costs, access, and best practices, hold public hearings, consult with experts, seek grants, and annually report to the legislature on findings and recommendations. The cost to DHHS would be partly dependent on the activity level of the council,



which is required to meet at least quarterly. Members would not be compensated but may be reimbursed for expenses.

- **Minnesota:** \$50,000 in fiscal year 2020 and \$50,000 in fiscal year 2021 are appropriated from the general fund to the Board of Regents of the University of Minnesota for the advisory council on rare diseases under Minnesota Statutes, section 137.68. The base for this appropriation in fiscal year 2024 and later is \$0.

The amount allocated to the Arthritis Research Program (Section 3 of the below model language) is an amount that may be determined by the state. It is simply the dollar amount the state wants to invest in treatments and a cure for arthritis while also investing in the state's universities and research institutions' research opportunities.

The language below also allows for the state to seek outside funds from the federal government, federal agencies, or private companies to offset costs. This has been done with RDAC throughout the country to limit the costs to the state.

## **Model Legislation**

### Section 1

The Arthritis Quality of Life Initiative is created in the Department of Health Human Services (DHHS).

- (1) The purpose of the Arthritis Quality of Life Initiative is to:
  - a. increase public awareness about arthritis, its symptoms, and available treatment options;
  - b. publicize options for arthritis prevention;
  - c. highlight the value of early diagnosis and treatment; and
  - d. encourage and facilitate the delivery of programs and services that are aimed at preventing arthritis-related complications and improving the quality of life of people with arthritis.
- (2) In establishing the initiative, DHHS must, at a minimum:
  - a. develop, and publicize on the DHHS website, a list of health care providers who offer specialized services for persons with arthritis;
  - b. implement a public information and outreach campaign that includes, but need not be limited to, appropriate educational materials that promote the early diagnosis and treatment of arthritis and other rheumatic diseases;
  - c. implement a professional education program for health care practitioners, which is to promote and endeavor to increase professional levels of expertise in association with the diagnosis of arthritis, the treatment and care of persons with the disease, and how health equity and disparities play a role in health outcomes for those with arthritis;
  - d. identify, and publicize on the DHHS' website, programs and services that are designed to prevent arthritis, reduce complications associated with arthritis, and improve the quality of life of those living with the disease;
  - e. establish a referral and support network to help arthritic persons identify appropriate health care providers, legal advocates, and available programs and services; and

- f. engage in, or promote and facilitate, the use of outcome-based research designed to improve arthritis care and treatment, and appropriately publicize the findings of such research.

## Section 2

The Advisory Council on Arthritis is created in the Department of Health and Human Services.

- (1) The purpose of the council would be to advise DHHS on the development and ongoing implementation and operations of the Arthritis Quality of Life Initiative.
- (2) The council would include 18 members, as follows: the Director of the Division of Aging Services in the Department of Human Services, the Principal Deputy Commissioner of Public Health in the Department of Health, the Director of Population Health in the Department of Health, the Director of the Division on Women in the Department of Children and Families, or their designees, who would each serve ex officio; and 14 public members who have expertise or experience in arthritis or related subject matters, to be appointed by the commissioner. The council must be composed of at least 4 patients with arthritis. Each public member of the council would serve for a term of three years, except that, to provide for staggered terms of the members first appointed, four would serve for terms of three years, five would serve for terms of two years, and five would serve for terms of one year. Each member is to hold office for the term of appointment, and until their successor is appointed and qualified. Members are eligible for reappointment to the council. The council would be required to organize as soon as practicable after the appointment of a majority of its members. The members would serve without compensation but could be reimbursed for travel and other necessary expenses incurred in the performance of their duties, within the limits of funds appropriated or otherwise made available to the council for its purposes.
- (3) The department shall provide professional and clerical staff to the council as may be necessary for the council's purposes, and the council shall also be entitled to call upon the services of any other State, county, or municipal department, board, commission, or agency, as may be available to it for its purposes.
- (4) In executing its duties under this act, the council shall consult with associations, organizations, and individuals who are knowledgeable about the needs of persons with arthritis.
- (5) In executing its duties under this act, the council shall convene public hearings, make inquiries, and solicit comments from the general public in [state] to assist the council with a first-year landscape or survey of the needs of arthritis patients, caregivers, and providers in the state.
- (6) In addition to any monies that may be allocated by the State for the purposes of the arthritis quality of life initiative, the department shall be authorized to accept any special grant of money, services, or property from the federal government or any of its agencies, or from any foundation, organization, or medical school, for the purposes of establishing and maintaining the initiative, or facilitating the activities of the advisory council.
- (7) Not later than 18 months after the bill's effective date, and annually thereafter, DHHS will be required to submit a report to the Governor and the Legislature describing the activities and accomplishments of the initiative.

## Section 3

The Arthritis Research Program is also created within the Department of Health and Human Services.



- (1) The purpose of the program is to fund research leading to new treatments for arthritis. The long-term goals of the program are to:
  - a. Improve health outcomes by researching better diagnoses of treatments and cures for arthritis in [state].
  - b. Research and identify best practices to reduce health disparities and achieve health equity in the research, diagnosis and treatment of arthritis in [state]Expand the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of arthritis in [state].
  - c. Stimulate economic activity in the state in areas related to arthritis research in [state].'
- (2)
  - a. Funds appropriated for the Arthritis Research Program shall be used exclusively for the award of grants and fellowships through a competitive, peer-reviewed process for research relating to the prevention, diagnosis, treatment, and cure of arthritis and for expenses incurred in the administration of this section.
  - b. Applications for arthritis research funding under the program may be submitted from any university or established research institute in the state. All qualified investigators in the state, regardless of institution affiliation, shall have equal access and opportunity to compete for research funding. The following types of applications may be considered for funding: Investigator-initiated research grants. Institutional research grants. Predoctoral and postdoctoral research fellowships. Collaborative research grants, including those that advance the finding of cures through basic or applied research.
- (3) There is created within the Department of Health the Arthritis Research Grant Advisory Board.
  - a. The board shall consist of 12 members appointed by the Secretary of Health and Human Services. The board shall be composed of members who have clinical experience with treating rheumatic diseases such as arthritis or experience in related biomedical research or have experience as a patient with arthritis. The Arthritis Research Grant Advisory Board must be composed of at least 2 patients with arthritis. Initial appointments to the board shall be made by December 31, 20XX. The board members shall serve 4-year terms, except that, to provide for staggered terms, six of the initial appointees shall serve 2-year terms and six shall serve 4-year terms. All subsequent appointments shall be for 4-year terms. The chair of the board shall be elected from the membership of the board and shall serve as chair for 2 years. An appointed member may not serve more than two consecutive terms. The board shall adopt internal organizational procedures as necessary for its efficient organization. The board shall establish and follow rigorous guidelines for ethical conduct and adhere to a strict policy with regard to conflicts of interest. A member of the board may not participate in any discussion or decision of the board or a panel with respect to a research proposal by any firm, entity, or agency with which the member is associated as a member of the governing body or as an employee or with which the member has entered into a contractual arrangement.
  - b. The department shall provide such staff, information, and other assistance as is reasonably necessary to assist the board in carrying out its responsibilities. Members of the board shall serve without compensation and may not receive reimbursement for per diem or travel expenses.
  - c. The board shall advise the Secretary of Health and Human Services as to the scope of the research program and shall submit its recommendations for proposals to be funded to the Secretary of Health and Human Services by December 15 of each year. Grants and fellowships shall be awarded by the Secretary of Health and Human Services, after consultation with the board, on the basis of scientific merit. Other responsibilities of the board may include, but are not limited to, providing advice on program priorities and emphases; assisting in the development of appropriate linkages to nonacademic entities, such as voluntary organizations, health care delivery institutions, industry, government

agencies, and public officials; and developing and providing oversight regarding mechanisms for the dissemination of research results.

- (4) The board shall submit a fiscal-year progress report on the programs under its purview annually to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the Secretary of Health and Human Services by February 15. The report must include:
  - a. A list of research projects supported by grants or fellowships awarded under the program.
  - b. A list of recipients of program grants or fellowships.
  - c. A list of publications in peer-reviewed journals involving research supported by grants or fellowships awarded under the program.
  - d. The state ranking and total amount of arthritis research funding currently flowing into the state from the National Institutes of Health.
  - e. New grants for arthritis research which were funded based on research supported by grants or fellowships awarded under the program
  - f. Progress toward programmatic goals, particularly in the prevention, diagnosis, treatment, and cure of arthritis.
  - g. Recommendations to further the mission of the program.
- (5) Implementation of the Arthritis Research Program is subject to legislative appropriation.
- (6) In addition to any monies that may be allocated by the State for the purposes of the Arthritis Research Program, the department shall be authorized to accept any special grant of money, services, or property from the federal government or any of its agencies, or from any foundation, organization, for the purposes of establishing and maintaining the program.

**Contact:** For more information on anything in this issue brief and/or model language, please contact Steven Schultz, Director, State Legislative Affairs for the Arthritis Foundation at [sschultz@arthritis.org](mailto:sschultz@arthritis.org) or [advocacy@arthritis.org](mailto:advocacy@arthritis.org).

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