



February 24, 2025

The Honorable Donald J. Trump
President
United States of America

The Honorable Robert F. Kennedy Jr.
Secretary
Department of Health and Human Services

Dear President Trump and Secretary Kennedy:

On behalf of the nearly 60 million adults and hundreds of thousands of children living with arthritis in the U.S., I am writing to express concern that recent Executive Orders and policies will hinder the ability of patient advocacy organizations and research institutions to carry out their mission-critical work and will ultimately harm arthritis patients. Specifically, we would like to call attention to the following:

- Executive Order: *Ending Radical and Wasteful Government DEI Programs and Preferencing*
- National Institutes of Health (NIH) Office of Policy and Extramural Research Administration (OPERA) policy announcement limiting the amount of indirect funding for research projects to 15%

Executive Order: *Ending Radical and Wasteful Government DEI Programs and Preferencing*

Arthritis affects everyone — it does not discriminate. Different communities experience different challenges in facing arthritis. The work of the Arthritis Foundation and many other patient advocacy organizations is vital to ensuring that everyone — whether they live in rural America or in a busy metropolitan area — has access to the information and resources needed to guide them on their patient or caregiver journey. The Arthritis Foundation envisions a world where all people with arthritis are living a life without limits.

On January 20, the Trump Administration signed the *Ending Radical and Wasteful Government DEI Programs and Preferencing* Executive Order. If enforced, many patient advocacy organizations who receive grants from the various agencies under HHS would be affected. Without these grants, entire organizations could shutter and individual programs will need to be shutdown, reducing the resources and information patients have access to as they navigate their disease. We urge the Administration to rescind this Executive Order.

NIH Office of Policy and Extramural Research Administration (OPERA) Indirect Cost Reduction

On February 7, NIH announced that they will be limiting the amount of indirect funding for research projects to 15% of the overall grant. Currently, the average rate of indirect costs for



a grant is 27%–28%. These indirect costs allow universities and other institutions who provide the infrastructure that underlies the arthritis research ecosystem to pay their bills. Indirect costs can support general upkeep, including shared facilities, lab equipment, and utilities, and they can also support personnel who keep the lab operating, clean, and compliant with safety regulations. Without this funding, scientists may not have the resources to make new discoveries about the mechanisms of disease or to complete clinical trials of new treatments. Non-profit research funding maximizes the impact of NIH investments in infrastructure by funding specific research projects that contribute to full utilization of NIH-funded infrastructure. There are no available sources of funding that would be able to replace the billions of dollars in NIH funding that would be cut by this proposed cap on indirect costs.

A Temporary Restraining Order was issued on the subject; and a federal judge in the U.S. District Court of Massachusetts extended that order, but only temporarily. We urge you and NIH to rescind this policy. If allowed to continue, it will hamstring research from basic science to clinical trials, cause turmoil across the research ecosystem by re-writing ongoing grant contracts and ultimately cost taxpayers even more in the long run by depriving patients of the advances in arthritis research and care that are necessary to address the number one cause of disability in the United States.

We appreciate your time and attention to this matter and urge the Administration to rescind both the Executive Order and NIH OPERA policy. As HHS and other agencies under the HHS umbrella continue to make decisions on new policy changes, we hope to serve as a resource representing patient voices and experiences of living with arthritis. If you have any questions or would like us to provide additional information, please contact Charles Husser at chusser@arthritis.org.

A handwritten signature in black ink that reads "Steven Taylor".

Steven Taylor, MBA
President and CEO
Arthritis Foundation

Cc: The Honorable Matthew J. Memoli, M.D., M.S.
Acting Director
National Institutes of Health