

May 5, 2025

The Honorable Robert F. Kennedy, Jr.  
Secretary  
Department of Health and Human Services  
2000 Independence Avenue SW  
Washington, D.C 20201

Dear Secretary Kennedy,

The American College of Rheumatology (ACR), which serves nearly 10,000 members, rheumatologists and rheumatology interprofessional care team members and the Rheumatology Research Foundation (RRF), write to share guidance during the reorganization of the National Institutes of Health as a part of the broader restructuring of the Department of Health and Human Services. The ACR has had the privilege of working closely with several NIH Institutes and appreciates the shared scientific partnerships fostered through advancements in rheumatic, musculoskeletal, and autoimmune disease research. On behalf of ACR membership, **we write in support of the crucial research and program conducted by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to address the impacts of chronic conditions and to express concern with the future of NIAMS should it be consolidated into another division**, particularly how the consolidation will affect the essential foundations like rheumatology specific activities conducted under the institute.

Rheumatologists are experts in the diagnosis and treatment of complex autoimmune and musculoskeletal conditions, including rheumatoid arthritis, psoriatic arthritis, osteoarthritis, juvenile arthritis, vasculitis, systemic lupus erythematosus, lupus nephritis, and multiple other debilitating diseases that require ongoing care. Among the chronic diseases that rheumatologists specialize in, arthritis stands out to the degree that it afflicts the American people. As the leading cause of disability in the United States, arthritis affects over 58 million (or 1 in 4) adults according to the CDC. However, a recent study suggests this number could be as high as 91 million (1 in 3). Clinical research programs at NIAMS research and combat the leading cause of disability in the United States.

Rheumatic diseases accumulate \$140 billion in medical costs each year, with an additional estimated \$164 billion in lost wages and productivity when degenerative conditions like osteoarthritis are included. The combined \$304 billion cost of rheumatic diseases is greater than the cost of cancer annually in the United States. Basic, translational, and clinical rheumatology research by programs like NIAMS develops treatments that prevent or mitigate disease progression, improve patient outcomes, and reduce the need for costly surgical interventions or procedures. Investing in this chronic care research allows for more opportunities for active and productive lives for patients and less costly healthcare interventions.

There are an estimated 300,000 children in the U.S. with juvenile arthritis who require specialized care from a pediatric rheumatologist. Earlier this year, President Trump created the Make America Healthy Again (MAHA) Commission with the task of improving our understanding of chronic disease, lowering the rates at which they occur, and preventing

childhood chronic disease. When announcing the Commission, the President highlighted the prevalence of autoimmune diseases among children as an example of the need to address the growing health care crisis in America. NIAMS has a significant role to play in combating juvenile rheumatic disease by supporting a dedicated pediatric rheumatology clinic and fellowship training program within the NIH. The ACR and NIAMS are aligned with the president's goal to mitigate childhood chronic disease.

To this end, the ACR supports NIH and HHS preserving NIAMS programs specific to rheumatic and musculoskeletal disease research, including:

- **The Accelerating Medicines Partnership Autoimmune and Immune-Mediated Diseases (AMP IM) program** to continue research on shared mechanisms of autoimmune and immune mediated diseases, particularly the cellular and molecular interactions that contribute to inflammation. This public-private partnership drives innovation and discoveries for some of the most debilitating rheumatic diseases such as lupus and arthritis.
- **The NIAMS Pain Research Program** to study gaps in knowledge regarding pain mechanisms in the body, biomarkers, and treatment options to prevent or alleviate pain. As many of the diseases under the NIAMS umbrella, including arthritis, cause pain, disability or disfigurement, this program meaningfully improves patient health and quality of life.
- **Restoring Joint Health and Function to Reduce Pain Consortium (RE-JOIN)** to study how sensory neurons with pain receptors connect to the joints and surrounding tissue. Understanding of the distribution of nerves in joint tissue will allow for advanced pain relief for arthritis patients. Project REJOIN is part of the larger NIH HEAL initiative, in which NIAMS plays a key role.
- **Adult and pediatric rheumatology fellowship programs**, both ACGME accredited, train the next generation of academic rheumatology leaders while conducting patient-based clinical trials.

Proposed reorganizations could combine NIAMS with other divisions like the National Heart, Lung, and Blood Institute (NHLBI), and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). While the ACR understands that the current NIH structure of organ-system specific research does not fully reflect contemporary understanding of the human body as an interconnected system – NIAMS research as structured is currently able to focus on the wholistic elements of human mobility and function by seeking to understand the causes, treatments, and prevention of the diseases affecting the bones, joints, muscles, skin and connective tissues.

The ACR is concerned that consolidation of NIAMS with other programs may negatively impact equity in funding distribution by crowding available resources, thus posing the risk of significant reduction in the rheumatology specific research needed to support millions of Americans living with chronic rheumatic disease.

Preserving the fundamental mission of NIAMS to support research into the causes, treatment, and prevention of arthritis, musculoskeletal and skin diseases; the training of basic and clinical

scientists to carry out this research; and the dissemination of information to further research progress in these diseases is paramount. We recognize the need to review the NIH's structure and strategic direction to determine changes to enhance efficiency and ensure future success. However, it is imperative that in structural review, essential elements of NIAMS role in the administration's mission to address chronic disease is not lost.

To this end, the ACR respectfully requests that you address the following questions in reorganization:

- How will reorganization ensure proper attention and allocation of resources to autoimmune disease research including arthritis and lupus?
- How will the work conducted and supported by NIAMS be embedded in any new institute, or within other HHS agencies?
- Given recent staffing changes at HHS, will current or new HHS staff be assigned to manage autoimmune, musculoskeletal and skin disease research within any proposed new institute which NIAMS will be a part?
- Who are NIH or HHS points of contact for researchers, including existing grant recipients and those with cooperative agreements, and who should grant recipients contact with questions regarding progress reports, budget, and programmatic changes?

Thank you for considering our input during this reorganization. The ACR looks forward to partnering with the NIH and HHS as new structures for the institutes within these organizations are considered. Please contact Lennie McDaniel, JD, Head of the ACR's DC Office at [LMcDaniel@rheumatology.org](mailto:LMcDaniel@rheumatology.org) should you have any questions or need additional information from the ACR or its membership.

Sincerely,



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Chair, Government Affairs Committee  
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