



August 16, 2023

Dear Congresswoman Kelly,

The undersigned 43 members of the NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases) Coalition, representing millions of Americans with chronic conditions and diseases of the bones, joints, muscles and skin, as well as the professionals who serve them, write in strong support of the National Institutes of Health (NIH) Clinical Trial Diversity Act (H.R. 3503).

The NIAMS Coalition is an independent consortium of [professional and voluntary organizations](#) with a national presence. Our organizations raise awareness about NIAMS' research into the basic understanding, causes, incidence, treatment, and prevention of diseases under its purview. The Coalition is a key partner of the Institute's work and strives to infuse the voices and interests of patients and professionals into everything it does.

An important priority of the NIAMS Coalition is working with all stakeholders, including the patient community, NIH, Congress, and others to increase clinical trial diversity and ensure that trials are representative of the populations most impacted by the diseases that are the subject of the trials. This includes populations that historically have been underrepresented in clinical trials, such as minorities, women, individuals with disabilities, and older adults who, in many cases, are among those most impacted by certain diseases. It is equally important that trials include participants who have different lived experiences and different socio-economic and educational backgrounds in addition to different demographic characteristics such as race, ethnicity, age, sex and sexual orientation. The lack of diverse representation in clinical trials can inhibit the ability of trials to determine whether a medication is safe and effective within that population and, ultimately, can limit the quality of care available to patients and further exacerbate health disparities.

The NIH Clinical Trial Diversity Act will help remove barriers that prevent diverse populations from enrolling in clinical trials, improving our ability to prevent, diagnose and treat diseases across the populations living with those diseases. The legislation builds upon current NIH policies as well as the DEPICT Act, which you championed, and which was signed into law as part of the Consolidated Appropriations Act of 2023. Specifically, the

bill would: require NIH to work with trial sponsors to improve recruitment and retention of participants who are representative of the disease or condition being studied; reduce the burden of trial participation; and launch a public awareness campaign across government agencies to raise awareness of the important opportunities that exist to participate in research.

One addition our coalition recommends is to add those with disabilities as an underrepresented population included within the bill. Consequently, any time race, ethnicity, gender, and sex are mentioned, so too should be disability. Individuals with disabilities are too often excluded from clinical research, and consequently are underrepresented in ways this bill tries to address.

The NIAMS Coalition believes that the NIH Clinical Trials Diversity Act represents a significant step forward that not only can ensure diversity in clinical trials, but also reduce health disparities and improve the health of all Americans. We are pleased to offer our support for this important legislation and look forward to working with you to enact the bill during the 118th Congress.

Please send an email to tricha@stopsarcoidosis.org with any questions.

Sincerely,

Tricha Shivas and Lee Grossman
NIAMS Coalition Co-chairs

List of organizations

American Academy of Dermatology Association

American Academy of Physical Medicine and Rehabilitation

American Association of Orthopaedic Surgeons

American College of Rheumatology

American Society for Bone and Mineral Research (ASBMR)

American Society of Nephrology

Arthritis Foundation

Autoimmune Association

cutaneous lymphoma foundation

Dermatology Foundation

Dermatology Nurses' Association

Dupuytren Research Group

Fearfully & Wonderfully Made Indianapolis Vitiligo Community, INC

Foundation for Ichthyosis and Related Skin Types

Foundation for Sarcoidosis Research (FSR)

FSHD Society

Genetic Alliance

GenTAC Alliance

Hidradenitis Suppurativa Foundation

International Foundation for AiArthritis

International Pemphigus & Pemphigoid Foundation

Loeys-Dietz Syndrome Foundation

Lupus and Allied Diseases Association, Inc.

Lupus Foundation of America

Lupus Research Alliance

Lymphatic Education & Research Network

Muscular Dystrophy Association

National Alopecia Areata Foundation

National Eczema Association

National Eosinophilia Myalgia Syndrome Network

National Organization for Rare Disorders

National Scleroderma Foundation

Orthopaedic Research and Education Foundation

Orthopaedic Research Society

Pachonychia Congenita Research and Patient Support Project

Parent Project Muscular Dystrophy

Pediatric Dermatology Research Alliance

PXE International

Rheumatology Research Foundation

Society for Investigative Dermatology

The Marfan Foundation

The Sturge-Weber Foundation

The VEDS Movement

U.S. Pain Foundation