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 polices 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@stopsarco.com 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
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