



Lindsey A. Criswell, M.D., M.P.H., D.Sc.
Director, NIAMS at the National Institute of Health
1 AMS Circle
Bethesda, Maryland 20892

January 12, 2024

Re: Docket No. NOT-AR-22-023; Request for Information on Themes for the NIAMS Strategic Plan for Fiscal Years 2025-2029

Dear Dr. Criswell,

On behalf of the more than 30 million Americans living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for issuing the Request for Information (RFI) regarding its strategic mission for fiscal years 2025 to 2029.

NORD is a unique federation of non-profits and health organizations dedicated to improving the health and well-being of people living with rare diseases by driving advances in care, research, and policy. NORD was founded 40 years ago, after the passage of the Orphan Drug Act (ODA), to formalize the coalition of patient advocacy groups that were instrumental in passing that landmark law. Since that time, NORD has been advancing rare disease research and funding to support the development of effective treatments and cures; raising awareness and addressing key knowledge gaps; and advocating for policies that support the availability of and access to safe and effective therapies.

NORD appreciates the opportunity to provide comments on this important strategic plan. Ensuring the unique needs and perspectives of patients with rare diseases are adequately reflected in the strategic plan is of key importance for our rare disease community. We appreciate the variety of highly important, cross-cutting topics represented in the strategic plan. These priorities will allow for meaningful progress in the overall area of arthritis, musculoskeletal disorders, and skin conditions, and greatly benefit rare disease patients with these conditions. NORD would welcome the opportunity to further elaborate on our specific comments with NIAMS officials at their convenience.

The NIAMS Coalition, of which NORD is a part of, has played a key role in ensuring that our patient community's voice is heard in data collection, as well as in other parts of research and that key fundamental concerns such as health disparities and limited predictability of preclinical research, are appropriately addressed. The Coalition's mission highlights the need for more data on (rare) diseases of interest to NIAMS and to improve access to care.

We thank you for your attention to our request and look forward to working with you to ensure

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that NIAMS has the resources it needs to serve the rare disease community. If you have any questions, please do not hesitate to contact Hayley Mason, Policy Analyst at hmason@rarediseases.org

Sincerely,

A handwritten signature in cursive script that reads "Hayley Mason".

Hayley Mason, MPA
Policy Analyst
National Organization for Rare Disorders

