FSR
Foundation for Sarcoidosis Research

October 25, 2026

Dr. Raymond Jacobson
Director, Center for Scientific Review
National Institutes of Health

RE: RFI on Proposed Changes to Reporting Outcomes from NIH Peer Review

Dear Director Jacobson,

Thank you for your leadership of the Center for Scientific Review (CSR) at the National Institutes of Health (NIH) and your efforts to enhance the research process. The Foundation for Sarcoidosis Research (FSR) is committed to ensuring ongoing expansion and advancement of our NIH research portfolio. We appreciate the opportunity to submit comments in response to the recent RFI titled, "Proposed Changes to Reporting Outcomes from NIH Peer Review".

FSR is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Sarcoidosis (pronounced SAR-COY-DOE-SIS) is an inflammatory disease characterized by the formation of granulomas—tiny clumps of inflammatory cells—in one or more organs of the body. When the immune system goes into overdrive and too many of these clumps form, they can interfere with an organ's structure and function. When left unchecked, chronic inflammation can lead to fibrosis, which is the permanent scarring of organ tissue, and even death. Sarcoidosis is particularly challenging to study because of its multi-organ, flaring, and heterogeneous nature.

Since its establishment in 2000, FSR has fostered over $11 million in sarcoidosis-specific research efforts. FSR is actively working with world leaders in sarcoidosis, investing in innovative, patient-centered research efforts and providing educational resources, support, and opportunities to accelerate research to patients worldwide. Our goals are to advance research and find a cure while educating the public and professional community and providing support to affected patients and families. Through the FSR Global Sarcoidosis Clinic Alliance and our FSR Scientific Advisory Board, FSR works closely with researchers to advance sarcoidosis research. Though we are proud of the research funding we have been able to raise over the last 25+ years, we know that our investment is just a drop in the bucket toward the level of investment in research that is required to advance the field and bring about advancements for those impacted by this complicated disease.

We deeply appreciate the unparalleled leadership of NIH in ongoing and emerging efforts to improve care for the community. Though there is always room for improvement, the current system of review at NIH has served the community well. We share the general concerns from the stakeholder community that the proposed changes would reduce transparency, facilitate non-scientific bias, and detract from objective numerical scoring and the significance of paylines.

Transparency in grant funding is the backbone for improved grantsmanship and clarity for researchers. The peer review process returns valuable feedback to the grant applicants allowing them to revisit key questions and to consider new aspects of the research aims and methodology they had not previously considered. Understanding how a research project does or does not fit into research priorities is vital to researchers for grant funding. Transparency around scoring is vital in helping grant applicants to determine the best way to address issues in grant proposals – i.e. should they revise and resubmit, emphasize different aspects of the research or work to better align with research priorities, or seek alternative funding. Transparency in the review process is important as it allows for more direct rebuttals, helps junior researchers grow thanks to feedback, and ensures proper credit is provided to researchers.

We believe that the proposed changes also will create a challenging bias in favor of more established investigators and against less experienced or early career researchers. Established investigators are often already familiar with study section expectations, but less established investigators need full transparency to better understand the grant writing process and improve their grants in a way that align with the grant funding expectations.

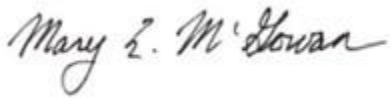
Moreover, we are concerned that some of the changes would align with the blocked uniform guidance proposal which could lead to a new system rife with inconsistency and implementation challenges. We remain supportive of any incremental progress that builds on the current, successful foundations in a transparent and collaborative way.

In order to advance more transparent research, we propose clarity in the review this process, and suggest providing a clear rubric of what metrics are used to determine grant funding to assist applicants with writing the most impactful grants. We propose that before changing the review process, the CSR host focus group discussions with researchers, including those from the rare disease researchers. We. further propose. that we maintain the current review standards until the

time at which a clearer consensus of the type of changes that would be most meaningful for transparency and research-based advancements.

Thank you for this opportunity to provide feedback.

Sincerely,



Mary McGowan, President and CEO
Foundation for Sarcoidosis Research (FSR)
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The following researchers join FSR in signing on to this letter:

Adam Anderson, MD
Pulmonologist, Missouri

Elizabeth Park, MD
Rheumatologist, New York

Barney Stern, MD
Neurologist, Maryland

Arthur Yee, MD, PhD
Rheumatologists, New York

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**Below please see additional feedback from one of FSR's Scientific Advisory Board Members**

The current review process provides input from a group of individuals expert in the science being evaluated but also from experts in closely allied fields. The multi-disciplinary evaluation process is not only a comprehensive assessment of the strengths and weaknesses of a research

proposal but is also a valuable educational resource for the research team submitting the application. This synergy will enhance not only the research proposal being evaluated but, importantly, future efforts by the research team. Maintaining a transparent, unbiased, and expert evaluation process ensures that current and future research initiatives promote the public good and enhance the overall quality of research initiatives.

Barney J. Stern, MD
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