

August 13, 2024

The Honorable Cathy McMorris Rodgers
House Committee on Energy and Commerce
United States House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chairwoman McMorris Rodgers,

As the world's largest organization for human genetics and genomics professionals, the American Society of Human Genetics (ASHG) appreciates the opportunity to comment on your proposed framework to reform the National Institutes of Health (NIH). Our approximately 8,000 members are researchers, medical geneticists, genetic counselors, and others who share the common goal of people everywhere realizing the full potential and benefits of human genetics and genomics research. The majority of ASHG members rely heavily on NIH funding to support their work and advance life-saving discoveries, treatments, and cures. ASHG understands the implications of the proposed recommendations and our comments reflect a diverse array of concerns and perspectives from our members.

First and foremost, ASHG would like to thank you for your longstanding support for NIH and the larger biomedical research enterprise. During your tenure, the investments made to NIH have ensured that our nation remains at the forefront of global competitiveness and has fostered innovative treatments and therapies that have saved thousands of lives. ASHG recognizes that as our nation's premier biomedical research agency, NIH must constantly evolve to optimize transparency and accountability and garner public trust. However, the Society is concerned that recommendations proposed in the framework would stifle much of the groundbreaking work supported by the agency.

Within the proposed framework, ASHG is primarily concerned about the consolidation of the existing 27 institutes and centers (ICs) into 15 newly formed ICs. This consolidation would require merging several existing ICs into larger, new ones. While this outcome might be beneficial, there is concern that consolidating into the proposed 15 new ICs might have unintended negative consequences for critical research priorities. Each IC is responsible for a balanced and nuanced research portfolio that reflects the needs and priorities of scientists and the most current science in their respective fields. Over the decades, with the expertise that each IC provides to NIH programs and initiatives, each IC has thoughtfully curated a unique perspective, direction, and portfolio that is distinct from any others. For these to be grouped together without extensive planning and feedback from stakeholders would set the research enterprise back years, derailing any current progress. For example, the National Human Genome Research Institute (NHGRI) is essential to the human genetics and genomics field to ensure that high-quality, ethical research is advanced. If consolidated into the same IC as the National Library of Medicine (NLM) and the National Institute of General Medical Sciences (NIGMS), the focus of this new institute would dramatically shift away from advancing and implementing genomic technologies. Notably, NHGRI has also spearheaded many initiatives that prioritize community engagement, the ethical and social implications of biomedical research, diverse research cohorts, and a strong research workforce. If the NIH is restructured, it is

unclear what would happen to these initiatives and which ICs would center these efforts. Changes to the NIH structure should enhance rather than undermine, existing trans-agency collaborations.

Furthermore, consolidation of the National Institute on Minority Health and Health Disparities (NIMHD) is deeply concerning and would be detrimental to NIH's broader mission to turn biomedical research discoveries into better health for all. Consolidating this IC would reduce the ability to address scientific workforce diversity and the supported research that aims to eliminate health disparities. As an example, the Diversity Centers for Genome Research – a collaboration led by NIMHD and NHGRI – supports genomic workforce development and innovative genomic research projects at institutions with a historic mission of serving underrepresented populations. Increasing the diversity of the biomedical research workforce positively impacts scientific innovation, global competitiveness, and the ability to deliver new insights into human disease and health.

Additionally, the framework proposes a congressionally mandated commission to oversee NIH's research programs and performance. ASHG urges you to reconsider this plan. Generally, NIH has carried out this crucial part of the oversight process through the work of advisory councils, which is made up of a diversity of distinguished researchers who meet multiple times a year to frame grant priorities and areas of investments for each IC. ASHG believes the high involvement of Congress in setting biomedical research priorities may lead to judgements that do not reflect scientific merit, which we believe should be the goal of research supported by NIH. Instead, these decisions should be made by scientists with expertise in their respective fields.

Thanks to your leadership, Congress has the opportunity to make significant reforms to NIH that will continue to spur innovation and improve health outcomes for all Americans. However, ASHG recommends that any steps taken to restructure or reform NIH include active participation from the agency's stakeholder community. In a time when scientific mistrust and miscommunication is prevalent, it is important that we work together to understand the needs of the biomedical research community. Critical to this effort is the need for stable funding, support for the biomedical research workforce, broad data sharing and management practices, and ensuring that researchers do not face undue burdens. Not only would this ensure that our nation's premier biomedical research agency can continue to maximize discoveries and spur innovation, but it would also ensure our talent and infrastructure can effectively address future public health challenges.

Thank you for your ongoing support for biomedical research and the opportunity to comment on your proposed framework. We welcome the opportunity to work with you and your staff as you further consider ways to revolutionize biomedical research. Please feel free to contact Karina Miller (kmiller@ashg.org) with any questions.

Sincerely,



Bruce D. Gelb, M.D.
President, American Society of Human Genetics