Testimony on behalf of the American Society of Human Genetics,
Gail Jarvik, MD, PhD, President.
Submitted to the House Appropriations Subcommittee on
Labor, Health, and Human Services, Education, and Related Agencies,
Fiscal Year 2022 Funding for the National Institutes of Health

May 19, 2021

The American Society of Human Genetics (ASHG) thanks the Subcommittee for its continued strong support and leadership in funding the National Institutes of Health (NIH). The $1.25 billion increase provided for Fiscal Year (FY) 2021 reinforces our nation's commitment to the health and well-being of all Americans—at a time when investing in biomedical research and scientific innovation is most needed to defeat the COVID-19 pandemic. **ASHG urges the Subcommittee to appropriate $46.1 billion for NIH in FY 2022.**

ASHG was delighted to see President Biden propose a major increase to NIH's budget in FY 2022. We note that President Biden proposes a significant investment for the creation of a new Advanced Research Projects Agency for Health (ARPA-H). We look forward to learning more about ARPA-H and how research on human genetics and genomics might play a role in its mission.

Saving Lives: Genetics Research in the Fight Against COVID-19

Less than a year after the first case of COVID-19 was reported, the U.S. Food and Drug Administration (FDA) authorized the use of two COVID-19 vaccines.[1] This record speed in vaccine development was built on decades of research and scientific knowledge, including NIH-funded basic research and private investments that have led to rapid and inexpensive DNA sequencing technologies.[2] Our ability to quickly and inexpensively analyze the genome of the SARS-CoV-2 virus has been crucial for developing

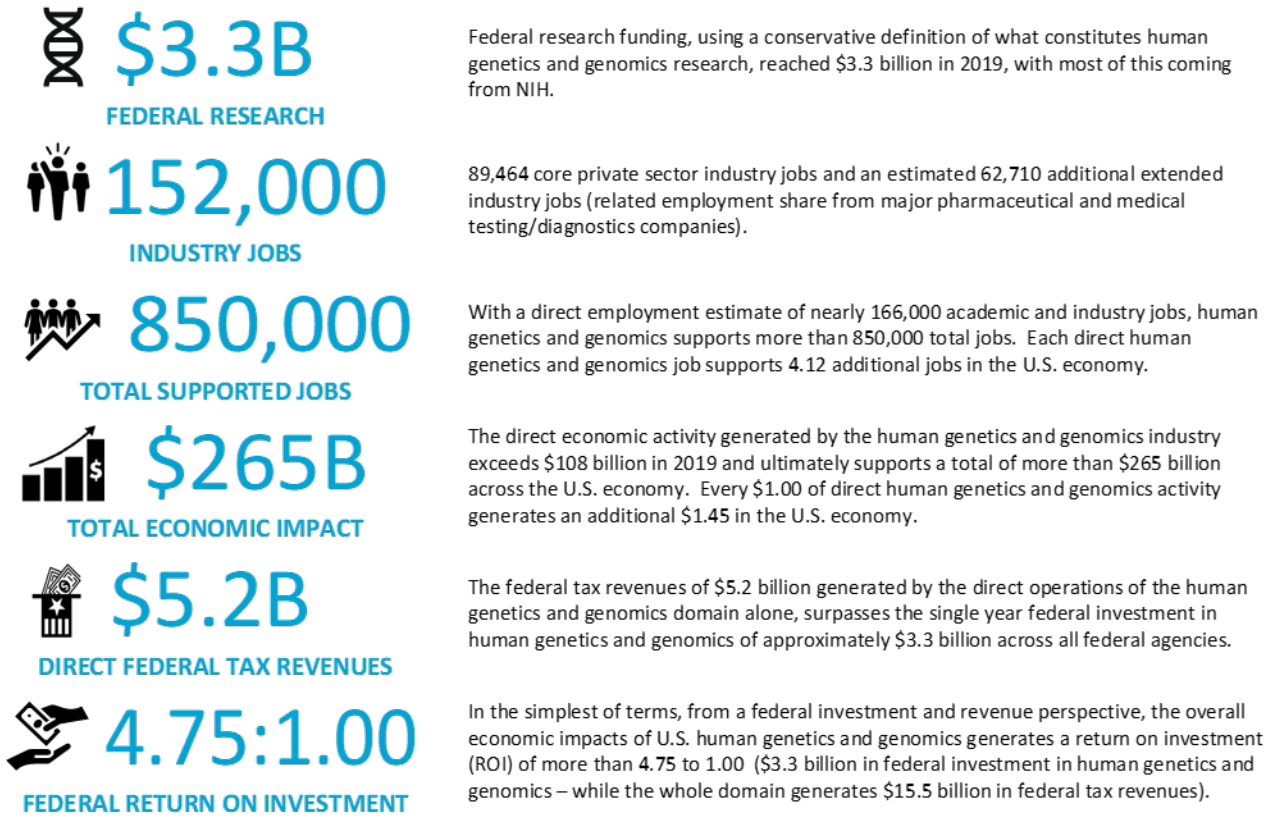
diagnostics and vaccines, testing, tracking variants, and trying to understand the range of responses to infection. NIH Director Dr. Francis Collins noted that the ability to rapidly sequence the new coronavirus "…made it possible within 24 hours for the first vaccine design to get started!"[3]

Human geneticists across the world mobilized quickly to try to understand why some individuals were asymptomatic while others suffered from severe disease, including so-called "Long COVID." Early data supports that genetic differences between individuals play a part in determining susceptibility to the disease. The COVID-19 Host Genetics Initiative and the COVID-19 Human Genetics Effort brought together researchers from dozens of countries to share resources and data to understand how human genetics affects COVID-19 susceptibility, severity, and outcomes.[4,5]

Return on Investment: Genetics Research Benefits the Economy

The pandemic has demonstrated that federally funded research is critical for us to return to normalcy and recover economically. In addition, investments in research and development continue to be a strong driver of economic activity overall. A new study commissioned by ASHG and conducted by TEConomy Partners highlights the growth of a dynamic ecosystem derived from human genetics research, and that the development and manufacturing of genomic technologies, diagnostics and therapeutics, and the associated healthcare services, "generate substantial U.S. economic activity and support a large volume of jobs across the nation."[6] The report estimates that the human genetics and genomics sector supports 850,000 jobs and generates $265 billion in total economic activity annually,[7] demonstrating that this sector has grown around five-fold in the last decade. Beyond the economic impact, the study also catalogues the many

ways in which human genetics and genomics is being integrated into routine clinical care across a broad range of diseases.[8] Key data from the report are shown below.



Genetics & Genomics: Striving for Equity

The COVID-19 pandemic has disproportionately affected racial and ethnic minorities in the U.S., reinforcing that there are social factors in this country that cause major health disparities.[9] It is imperative that the application of genetic science in healthcare does not worsen existing health disparities, but instead advances health to benefit all Americans. Indeed, NIH-funded research has demonstrated how genetics and genomics research can be a tool for health equity through deliberate inclusion and participation of individuals from diverse groups. As genetics research is foundational to our understanding of human biology, gleaning the full scope of genetic variation will improve both healthcare and health equity. Inclusion of populations from diverse ancestries in

studies is revealing novel insights about drug responses, diagnostic accuracy, and disease risk, demonstrating the need for increased diversity in research studies and clinical trials.[10] In ensuring broad cohort diversity in biomedical research, we need to consider all types of diversity, including engagement with both urban and rural communities, and taking into account social demographics such as gender, age, and economic status.

The Society commends NIH's efforts to advance diversity and equity in research, which are made possible by the strong support of this Subcommittee in providing robust funding for the NIH. The great strides made by the All of Us Research Program in having its research cohort reflect the diversity of the United States is one such example.[11] Furthermore, UNITE, NIH's new initiative to address "racial equity in the biomedical research workforce" and "long-standing health disparities and issues related to minority health inequities in the United States"[12] comes at a crucial time for our nation.

America's greatest asset is its people—all of its people. From the research workforce to research participants, increasing diversity is essential if we are to realize the full promise of genomics research and the equitable application of genetic discoveries in healthcare and society. Sustained budget increases for NIH are necessary to fund programs that emphasize diversity and equity in the workforce and that broaden participation by the public in research.

NIH Funding for the Future

The COVID-19 pandemic caused unprecedented disruptions to the biomedical research enterprise in 2021. This was especially true in the human genetics and genomics

community, where researchers either closed laboratories or repurposed their genome sequencing machines for performing SARS-CoV-2 testing, tracking and tracing. Strong funding is needed in FY2022 to help the workforce recover.

ASHG joins its fellow members of the Federation of American Societies for Experimental Biology (FASEB) and the Ad Hoc Group for Medical Research in recommending a **$46.1 billion base budget for NIH for FY 2022.** This funding level would allow NIH's base budget to keep pace with inflation, specifically the biomedical research and development price index, and support crucial research on human genetics and genomics across all of the NIH's 27 Institutes and Centers.

The American Society of Human Genetics (ASHG), founded in 1948, is the primary professional membership organization for human genetics specialists worldwide. The Society's nearly 8,000 members include researchers, clinicians, genetic counselors, nurses and others who have a special interest in the field of human genetics.

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[1] https://covid19.nih.gov/research-highlights/vaccine-development
[2] Ibid.
[3] https://www.forbes.com/sites/billfrist/2021/01/20/nih-director-dr-francis-collins-connecting-the-dots-from-the-human-genome-project-to-the-covid-19-vaccine/?sh=36f948a27543
[4] https://www.covid19hg.org/partners/
[5] https://www.covidhge.com/
[6] Tripp, S., and Grueber, M. 2021. The Economic Impact and Functional Applications of Human Genetics and Genomics. https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEConomy-Impact-Report-Final.pdf
[7] Ibid.
[8] Ibid.
[9] https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html
[10] Collins, F., Doudna, J.A., Lander, E., and Rotimi, C.N. Human Molecular Genetics and Genomics — Important Advances and Exciting Possibilities. N.Engl.J.Med 2021. 384:1-4
[11] https://allofus.nih.gov/
[12] https://www.nih.gov/ending-structural-racism/unite