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Expression of concern for global biomedical research by the human genome organization (HUGO)

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Abstract
Cuts to US science funding will stall advances in genomics affecting public health, rare disease and cancer diagnostics and therapeutics in the US and around the world.

The United States of America has been the world leader in biomedical research for 80 years. Since the end of World War II, the USA has been a beacon for the best international students and trainees who are drawn to US laboratories and residencies where they develop into outstanding researchers and clinicians. Upon returning to their home countries, they enrich global academic and biomedical research. Many of those who choose to stay in the US, become leaders in academia and industry through their creativity and initiative. This has benefited the US and beyond, both scientifically and economically.

The Human Genome Organization (HUGO) was founded in 1988 with a commitment to ensure that the benefits of the human genome project, then in its infancy, would accrue to all of humanity [1]. The completion of the reference human genome sequence [2] and its subsequent improvements has led to enormous scientific advances. Nevertheless, we are all still limited by the paucity of genomic data from global populations who suffer from an inequity of access to genomic sequencing and genetic counseling [3, 4].

The economic return on investment for the human genome project is estimated to be $140 for every dollar of the original funding. For example, in 2019, the $3.3 billion invested by the US federal government for genetics and genomics research, mostly by the US National Institutes for Health (NIH), resulted in an overall economic impact of $265 billion, with $5.2 billion generated in direct federal tax revenues [5].

Recent announcements of cuts to funding for the NIH, National Science Foundation (NSF), the Centers for Disease Control and Prevention (CDC), and other science agencies, as well as pervasive cuts in foreign aid, including scientific funding, will stall the remarkable progress already made in early diagnosis and precision treatments for cancer, the identification of infectious agents, and the crucial impact of genome sequencing to shorten the diagnostic odyssey for thousands of rare diseases which affect 1 in 10 people around the world and the ability to develop tailored treatments for these conditions. The US is a nation of immigrants. Knowledge of human genomic variants and their frequencies from populations around the world is of direct clinical benefit to US citizens. The support of human and animal model genomic resources,

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databases, and knowledgebases is fundamental for modern biomedical education, research and clinical care.

Funding for research through the US NIH benefits every state in the US as well as international scientific efforts. Biomedical research knows no national borders or political persuasions. The free exchange of scientific knowledge is a hallmark of biomedical research and is a founding principle of HUGO and the human genome project. Funding for research at NIH and CDC has led to effective vaccines for the COVID and Ebola viruses. International funding to build capacity for genome sequencing through initiatives such as Human Heredity and Health in Africa (H3Africa) allowed funded centers in South Africa and Nigeria to rapidly detect new SARS-CoV-2 mutations and adjust vaccines accordingly. The existence of rapid response teams from the CDC has limited outbreaks of Ebola and Marburg virus infections in Africa. The lack of funding for that same response now risks broader spread of a strain of Ebola that is not prevented by the current vaccines. While Uganda may seem very far off and of no concern to the US population, global international flights mean that any virus is only hours away from entering the US. Public Health is an essential undertaking in any society. If it is effective, it is largely invisible. Novel infectious agents are identified, vaccines are administered, and case tracing limits outbreaks.

HUGO remains committed to ensuring that the benefits of the human genome project accrue to all of humanity. Those benefits cannot be realized until more populations are sequenced in their own countries and the health implications of that sequencing are extended to population screening and genetic counseling of at-risk families. Furthermore, that diversity must be catalogued and globally accessible in managed ways so that individuals of any origin can be diagnosed, counseled and treated appropriately, regardless of where they live. HUGO advocates strongly not only for continuation of prior funding levels but for further increases in US research funding for genetics and genomics, as well as funding for the broader biomedical and scientific research efforts.

Author contributions

A.H. wrote the main manuscript text. J.V. and A.B. revised it. A.H. is the President of HUGO and P.C. is the Vice President at the time of submission. All authors are members of the HUGO Executive Board and have reviewed and approved the final version of the manuscript.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Competing interests

The authors declare no competing interests.

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