

American Society of Human Genetics



Facing Our History - Building an Equitable Future Initiative

Acknowledgments

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Executive Summary

Overview of the Initiative

This “Facing our History—Building an Equitable Future” report is the product of a major year-long initiative to acknowledge and reckon with past injustice, as well as progress toward justice, within the American Society of Human Genetics (ASHG) and the broader human genetics field. Approved by ASHG’s Board of Directors in 2020 and launched in 2021, the initiative is one element of a multifaceted effort by the Society to underscore and undertake a commitment to greater diversity, equity, and inclusion in pursuit of its vision that *people everywhere realize the benefits of human genetics and genomics research*.

The initiative was undertaken with support and input from an expert panel of human geneticists, historians, clinician-scientists, equity scholars, and social scientists that was charged to explore historical occurrences through the context of human genetics and research; document ASHG’s past role in generating, disseminating, or promoting harms that have helped contribute to the evolution and institutionalization of injustices, with a focus on racism; acknowledge key paradigm shifts toward justice; and remain mindful of the contours of current controversy linked to issues rooted in history.

The main activities of the initiative include:

- A Research and Environmental Scan of the human genetics and genomics field and ASHG’s history to identify examples of unethical or unjust views, actions, events, or statements. The scan also identified significant areas of progress, including trends or key moments of movement toward greater justice, equity, and inclusion.
- Four Expert Panel meetings during which the panel reviewed and provided feedback on the findings of the Research and Environmental Scan, helped identify key themes, and developed insights for actions ASHG could undertake.
- A Community Dialogue session during which members of the ASHG community learned about early findings from this initiative, engaged in discussion with Expert Panel members, and provided additional potential insights for action.

Overview of the Findings

The Research and Environmental Scan’s purpose was to better understand and document a history of past indiscretions linked to racism, eugenics, or other systemic forms of injustice in the Society and human genetics field. The scan included hundreds of resources such as peer-reviewed literature, published literature, interviews, and speeches. Its findings were used to inform the Expert Panel’s work, which was guided by three questions:

- To what extent has human genetics research permeated and promoted scientific racism?
- How has human genetics research been used (within or beyond genetics) as a justification for systematic exclusion, mistreatment, and abuse of people from racial and ethnic minoritized groups, people with invisible and visible disabilities, and other historically marginalized groups?
- Where and when have geneticists spoken out against the misuse of genetic knowledge to justify harm?

Appreciating that there is a tremendous depth and breadth of historical, sociological, political, and medical literature and scholarship on these topics both in the U.S. and around the world, the ASHG Board of Directors anticipated and directed that the report could not be exhaustive in recounting the

breadth of all incidents nor could it document incidents in depth. Rather, it would be a vital investigation and reporting of exemplar activities and actions that highlight and summarize key relevant views, actions, events, or statements from the field of human genetics and genomics and the history of ASHG. Additionally, the timeframe covered for the Research and Environmental Scan was from the period of ASHG's founding (1948) to the present day, although the report does address key antecedent views and events relevant to the Society's founding. Finally, the report primarily focuses on experiences in the United States; however, it addresses the United States' influence in the international context and acknowledges international issues that significantly impacted experiences in the United States.

The findings from this work were divided into four themes, discussed in detail below.

ASHG and the American Eugenics Movement

Eugenic ideologies were embedded into American science, politics, and society in the first half of the 20th century. Eugenics exploited preexisting prejudices and promoted the idea that "unfitness" was genetically determined. Extreme measures such as sterilization and genocide were utilized to restrict the proliferation of people deemed "unfit." However, after World War II and the realization of how American eugenic policies inspired the atrocities of Nazi Germany, public popularity of eugenics collapsed. Given that genetics was misused as a scientific basis for eugenic ideologies, the study of human genetics was seen as controversial after World War II. The founders of ASHG recognized this and established the Society to restore credibility to the field of human genetics. However, ASHG could not fully distance itself from the legacy of eugenics. Some of ASHG's early leaders had histories of advocating for or participating in eugenic interventions or holding leadership positions in eugenics associations.

ASHG was Silent when Genetics was Misused to Justify Social Harms

In the 1960s and 1970s, human genetics was frequently and erroneously used to provide false foundations for discrimination or perpetuate racism. A few examples include beliefs that people from minoritized groups were intellectually inferior due to genetic predisposition; negative stereotypes about individuals with XYY syndrome; and discrimination against Black people based on sickle cell status. In 1967, as genetics increasingly became a basis for social and political matters, ASHG established the Social Issues Committee. However, this committee failed to publicly address key issues of the time due to its stance to not issue statements or directives surrounding controversial topics.

ASHG's Evolving Role to Advance Ethical and Legal Protections

As human genetics research became more advanced, there were calls to consider the ethical implications of genetics studies and methods. Within the field, two projects came under increased scrutiny due to their ethical implications: the Human Genome Diversity Project and Arizona State University's research involving the Havasupai Tribe. Also, as the Human Genome Project offered the promise of unprecedented insights into human genetics, there were concerns that the findings could be used as the basis for discrimination based on genetic information. ASHG recognized these concerns and released guidance about how information obtained through genetic testing could be used in discriminatory manners. ASHG was also an early supporter and strong advocate for the Genetic Information Nondiscrimination Act (GINA), which protects individuals from discrimination by employers and health insurance companies.

ASHG Strives for a More Equitable and Just Future

While the Human Genome Project was a significant endeavor that contributed to the knowledge that there is no scientific or genetic basis for biological race in humans, some individuals and entities continued to use genetics to promote ideas of racial hierarchy. These claims were met with widespread criticism, including some strongly worded statements from ASHG. The Human Genome Project also highlighted the need for more diversity among genetics and genomics research participants and within the workforce. Several initiatives were developed to engage individuals from historically excluded groups in genetics and genomics research. With its [Diversity and Inclusion Policy Statement](#), ASHG established its commitment to Diversity, Equity, and Inclusion (DEI) within ASHG as well as in the broader genetics and genomics community.

Note on Language

As a human genetics research organization, ASHG understands that concepts and terms such as “race,” “ancestry,” and “ethnicity” are socially defined categories that have shifted over time based on cultural norms and beliefs. That said, this report may use these terms if they were used during the period being discussed or specifically quoted in a historical resource, action, or policy. When describing genetic findings or research, we refrain from utilizing racialized groups and refer to geographical ancestry (e.g., African ancestry, European ancestry, Asian ancestry), which though also imperfect and socially constructed, are currently more relevant to genetic variation.

In addition, some terms in this report regarding eugenic ideologies such as “feeble-minded” and “unfit” were drawn from the literature and retained to exhibit the phraseology of the time. Instances of these terms in the report will be in quotations.