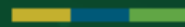


American Society of Human Genetics



Facing Our History - Building an Equitable Future Initiative

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Expert Panel Members

- Neil Hanchard, MD, D.Phil - Facilitator
- Katrina Claw, PhD
- Tshaka Cunningham, PhD
- Evelyn Hammonds, PhD
- Gail P. Jarvik, MD, PhD
- Rick Kittles, PhD
- David L. Nelson, PhD
- Robert Nussbaum, MD
- Charmaine Royal, PhD
- Timothy Thornton, PhD
- Sarah Tishkoff, PhD
- Digna Velez Edwards, PhD
- Ambroise Wonkam, MD, PhD

ASHG Staff

- Mona V. Miller, MPP – Chief Executive Officer
- Chazeman Jackson, PhD, MA – Senior Director, Diversity, Equity, and Inclusion
- Maya June – Diversity, Equity, and Inclusion Specialist

ASHG Community Dialogue participants

Ripple Effect Communications, Inc.

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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.

Findings

Introduction

The findings for this initiative are divided into four themes. Each theme begins with an overview of relevant happenings in the broader human genetics field and is followed by an overview of historical occurrences at ASHG. Each theme includes a callout box that delves deeper into key events and highlights influential geneticists from minoritized groups. The findings from this initiative are not exhaustive but illustrate key figures, statements, and events that fall within the parameters of the research and environmental scan methodology.

ASHG and the American Eugenics Movement

Contextual Background of Eugenics

The term “eugenics” was first coined by Francis Galton in 1883, and was defined as “the science of improvement of the human race germ plasm through better breeding.”^{1,2} Over time, the definition and implication of the term evolved, but overall, eugenics still refers to a belief that traits deemed ‘undesirable,’ some of which have no biological underpinning, could be eliminated from the population by manipulating genetic inheritance of traits.³ Eugenics was not confined to scientific circles, as support for eugenic beliefs became commonplace in society. Eugenic theories and ideologies moved readily into the mainstream of society because they tapped into, and added a new “pseudoscientific” context for, widespread pre-existing prejudices including racism, classism, xenophobia, antisemitism, ableism, and sexism, which, in turn, were the basis for ‘undesirable’ categorizations.⁴ These prejudices long predated eugenic theories and have served to justify other societal tragedies such as colonialism, imperialism, and slavery.⁴ Eugenics theories also legitimized the development of policies and practices to limit the autonomy and capacities of people who were deemed “unfit” for society, which led to various atrocities on a massive scale.² For example, eugenicists promoted and helped pass policies authorizing marriage restrictions, institutionalization, sterilization, abortion, and castration as means to restrict the reproductive autonomy of those deemed “unfit.” The most extreme methods became the basis for forced sterilization laws across the globe and the “racial hygiene” policies of Nazi Germany which led to the genocide of Jewish people; minoritized ethnic communities, such as the Sinti and Roma; individuals with disabilities; and LGBTQ+ individuals.^{4,5}

Origins of the American Eugenics Movement

In the late 1800s and early 1900s, the eugenics movement gained popularity in America. The rediscovery of Mendel’s laws of inheritance led to beliefs that most traits, including those deemed as “unfit,” were genetically determined and passed from parents to their children.^{6,7} During this time there were concerns about perceived negative societal impacts of those who were deemed “unfit,” which included people in poverty, people with mental disabilities, criminals, and people of certain racial and ethnic identities.⁶ There were also fears that “Anglo-Saxon superiority” was under threat as immigration from eastern and southern Europe increased and slavery ended in the United States.⁶ This combination of the rediscovery of Mendel’s laws and social anxieties laid the groundwork for eugenic beliefs that the transmission of socially unacceptable traits could be controlled by restricting the procreation of people who possessed those traits.⁶ During the height of the eugenics movement in America, eugenic ideals and principles became commonplace in science and society through the establishment of research programs that investigated the potential genetic underpinnings of eugenic beliefs; forced sterilization policies that

restricted procreation by people who were deemed “unfit;” and associations that promoted eugenic thinking to society at large.

In 1910, Charles Davenport helped further embed eugenic ideals into genetics research by establishing the Eugenics Record Office (ERO) of the Carnegie Institute of Washington at Cold Spring Harbor, New York.⁶⁻¹⁰ The two main activities of the ERO were to investigate the potential genetic underpinnings and the policy implications of eugenic ideals.^{6-8,11} The research studies at the ERO surveyed families and created pedigrees to study the heredity of numerous attributes, including socially undesirable traits such as, “feeble-mindedness,” “criminality,” and “alcoholism.”⁸ During his time at the ERO, Davenport studied “mixed-race” individuals with African and European ancestry because he was concerned that those who could pass as White would pollute the White gene pool.¹¹ Davenport also developed methods to detect individuals who were passing as White by examining hair curl patterns and using an instrument to quantify skin color.^{10,11} This fear of racial mixing was also a key driver of the ERO’s political advocacy.

The ERO’s policy priorities included restrictions on immigration of individuals to the U.S. from non-English-speaking countries and forced sterilization of “eugenically unfit” American citizens.^{6,8,10,12} Harry Laughlin, the superintendent of the ERO, used his position as the expert eugenics agent on the House Committee on Immigration and Naturalization to push unfounded and heavily criticized claims that immigrants from non-English-speaking countries were biologically inferior and that racial mixing would be deleterious to the perceived “American Race,” which consisted predominantly of people with Nordic and western European ancestry.^{5,6,8,10} In part because of the ERO’s efforts, the Johnson Restrictive Immigration Act of 1924 passed, which restricted immigrants from southern and eastern Europe and Asia from entering the United States.^{6-8,10} Laughlin also developed a model sterilization law that was used as a blueprint for involuntary sterilization laws in several U.S. states and in Nazi Germany.^{6,10,12} By 1931, 30 U.S. states had involuntary sterilization laws that targeted people with mental and physical disabilities, people in poverty, and racial and ethnic minoritized groups, including African Americans, Mexican Americans, and Native Americans.^{6,13-18} While the ERO was a major driver of the scientific and political progress of the American eugenics movement, the work of the American Eugenics Society (AES) drove the societal progress of this movement.

The AES was established in 1926 to promote racial betterment and eugenics by educating the general public about the benefits of eugenics programs.^{8,12,19} Laughlin was one of the founders, and Davenport served as the first vice president.^{8,12,19} At the height of AES’ popularity in the 1930s, there were 1,260 members, most of whom were from prominent wealthy families with no scientific backgrounds.^{8,12,19} AES hosted traveling exhibitions that underscored the perceived financial and societal benefits of eugenics programs through displays with questionable statistics that overestimated the birthrates and the economic toll of the “unfit.”^{8,12,19} These exhibitions would travel to county fairs and host “Fitter Family” competitions that determined which families would have the “fittest” children based on appearance, behavior, intelligence, and health.¹⁹ However, starting in the late 1930s, the mainstream popularity of eugenic ideologies waned.

As the public learned how scientists and politicians in Nazi Germany used eugenic ideals to justify the atrocities and genocide they committed during the Holocaust, the public and scientific community became increasingly critical of and horrified by eugenics.^{5,8,10,20} It was especially concerning when the public learned that eugenics-based policies in Nazi Germany, specifically their sterilization policies, were inspired by Laughlin’s model sterilization law in the United States.^{8,21} These realizations led to various

groups distancing themselves from eugenics. In 1939, the ERO closed after a Carnegie Institute of Washington committee found that eugenics research lacked validity due to the “heavy reliance on anecdotal evidence.”^{8,10} Most states reduced or ceased state-sponsored eugenic sterilizations (North Carolina and Georgia were exceptions).^{22,23} By the 1960s, the membership of AES dropped to 400 people from scientific and medical fields.^{12,19,20,24} The new demographics of AES reflected the society’s shift from a focus on race and class-based eugenics to a focus on “trends of human evolution and the biological, medical, and social forces that determine these trends.”^{12,24,25} The society further distanced itself from its eugenic origins when it changed its name to the Society for the Study of Social Biology in 1972.^{12,19,20,24,25}

Given that human genetics was used as the scientific basis for eugenics, its study was controversial after World War II.²⁶ The response by the broader genetics community was mixed, with some considering the study of humans to be too controversial and too difficult. Among those studying human genetics, some researchers believed that eugenic principles merited further study, while others were worried that the continued study and support of eugenics as a viable science would taint the credibility of human genetics.^{5,20,25,27} The founders of the American Society of Human Genetics (ASHG) recognized the need for the human genetics community to separate itself from eugenics and established the society in the hopes of establishing the credibility of human genetics through the “furtherance of sound research.”^{26,27} Despite these intentions, some of ASHG’s founders and early leaders had troubling associations with eugenic ideals, practices, and organizations.

ASHG’s Association with the Eugenics Movement

The formation of ASHG in 1948 was controversial at the time, given the association of eugenic principles with human genetics research following World War II.²⁶ The founders of ASHG hoped that the Society’s founding would advance sound human genetics research in response to the misuse of genetics for eugenics.²⁷ Despite initial intentions to distance the field of human genetics from eugenics, the specter of eugenics followed ASHG. Some of ASHG’s early leaders had histories of advocating for or participating in eugenic interventions or holding leadership positions in eugenics associations.²⁰ From the founding of the AES to its name change in 1972, nine ASHG presidents served on its board of directors or as presidents of AES (Laurence Snyder, Lee Dice, Franz Kallmann, Clarence Oliver, Claude Nash Herndon, Sheldon Reed, Frank Clarke Fraser, Bentley Glass, and Victor McKusick).^{20,25,28–30} Of the ASHG presidents who served in AES leadership positions, three (Snyder, Oliver, and Glass) served in leadership positions in AES during their time as president of ASHG.^{20,28–30} Additionally, ASHG, as an organization, collaborated with AES and held a joint symposium about genetics and intelligence during the 1953 American Association for the Advancement of Science (AAAS) meeting.^{31,32} While these presidents primarily served leadership roles in AES during its transition away from class and race-based eugenics, AES still supported eugenics-based population control interventions, some of which employed directive and coercive methods.^{19,20,25}

Several ASHG presidents at some point in their careers supported both voluntary and compulsory eugenic sterilizations. Lee Dice (ASHG President, 1951) believed that sterilization was a “practical way” to prevent the spread of “harmful genes;” however, Dice stipulated that sterilization should be voluntary, except in “the most extreme cases of irresponsibility.”³³ Curt Stern (ASHG President, 1957) shared similar beliefs to Dice’s, namely, that people with “serious hereditary defects” should be institutionalized or involuntarily sterilized if they resisted recommendations not to have children.⁸ Franz

Kallmann (ASHG President, 1952) advocated for compulsory sterilization of people with schizophrenia and their relatives, even if the relatives did not exhibit symptoms of schizophrenia.^{29,30} Madge Macklin (ASHG President, 1959) considered people with heritable diseases that caused physical disability public health threats and suggested sterilization as a method to prevent the spread of genetic diseases.²² Laurence Snyder (ASHG President, 1950) believed that the subjective trait of ‘feeblemindedness’ was among traits that were “so undesirable that the race could well do without them,” and suggested that sterilization was a simple procedure to ensure that these unfavorable traits did not proliferate in society.²² These ASHG presidents expressed views that promoted eugenic control of individuals’ reproductive autonomy. Additionally, one ASHG president, Claude Nash Herndon, was an active participant in a state-sponsored eugenics sterilization program.

Herndon was a key participant in North Carolina’s eugenic sterilization program, for which he provided guidance and performed involuntary sterilization on those found to be “unfit” (see callout box for more details about North Carolina’s eugenic sterilization program).^{29,34,35} Herndon was also a key advocate for naming ASHG’s highest award after his mentor William Allan, a eugenicist who promoted sterilizations of individuals with undesirable traits that had a “strong” genetic basis.^{22,29,36} Allan saw people with disabilities as economic burdens and was against welfare programs which he saw as “the State...trying to salvage the blind, the deaf, the crippled, and the feeble-minded children.”²² Allan believed that eugenics programs would be effective in reducing the share of “the State’s defective dependents.”²²

While some ASHG presidents embraced eugenic ideals and practices, others were critical of eugenics based on its reliance on racism and coercive practices. In 1932, H.J. Muller (ASHG President, 1948), criticized the eugenics movement during the Third International Eugenics Congress, stating that it was “the naïve doctrine that the economically dominant classes, races, and individuals are genetically superior.”³⁷ In the preface to the first issue of the *American Journal of Human Genetics (AJHG)*, Muller continued to criticize eugenics for its purpose of “translating biological prejudice into action,” by promoting classist and racist ideals that have no basis in genetics.^{20,27} James Neel (ASHG President, 1954) was critical of eugenics and the use of coercive, directive genetic counseling practices that swayed family planning decisions.²⁰ Leslie Clarence Dunn (ASHG President, 1961) co-authored UNESCO’s 1951 Statement on Race which concluded that race was a social construct with negligible scientific utility and rejected scientific justifications for racism.^{38,39} While Glass (ASHG President, 1967) was a director of AES, he rejected race-based eugenic arguments that centered around Black inferiority and fears of racial mixing.⁴⁰ He believed that environmental factors explained disparities between racialized groups and supported desegregation efforts as a means to lessen those disparities.⁴⁰ However, he still believed that eugenics could be used to positively influence human heredity.⁴⁰

While this research and environmental scan did not find specific activities or positions that ASHG as an organization adopted that directly aided in furthering the eugenics movement, it also did not find documentation that ASHG took a strong stance to block membership or inclusion in forums by people who espoused eugenic theories or ideals. However, starting in the 1990s, papers published in Society journals and ASHG statements opposing eugenic theories and actions were a part of the scientific record. For example, a 1991 review article in *AJHG* asserted the importance of health professionals and geneticists “reflect[ing] with great concern on the history of eugenics, so that we do not repeat the pattern.”⁶ In 1999, ASHG published an organizational position statement in *AJHG*, titled “Eugenics and the Misuse of Genetic Information to Restrict Reproductive Freedom,” stating that ASHG “deplores laws, governmental regulations, and any other coercive effort intended to restrict reproductive freedom or to

constrain freedom of choice on the basis of known or presumed genetic characteristics of potential parents or the anticipated genetic characteristics, health, or capacities of potential offspring.”² Over decades, some ASHG presidents and field leaders used their presidential addresses to raise and discuss the legacy of eugenics and repudiate its harms.

Sterilization Laws

In the 20th century, approximately 70,000 Americans were forcibly sterilized as part of state-sanctioned eugenic sterilization programs.^{14,41} In 1907, Indiana passed the nation’s first involuntary-sterilization law, and by 1931, 30 states had similar laws.^{6,14} These laws—built on a premise of “negative eugenics” in which reproduction was discouraged for people perceived to have genetic “defects” or “undesirable” traits or conditions—were used to target people who were institutionalized for mental or physical disabilities and deemed “feebleminded” or “mental[ly] defective.”^{6,14,41} Prior to the passage of these laws, some eugenicists sought to restrict the reproductive potential of people with mental and physical disabilities by segregating them from society in colonies or institutions until they passed reproductive potential.⁴¹ However, it became expensive to keep people isolated, making sterilization an alternative that allowed people to be released from the institutions after the procedure.⁴¹ Sterilization laws were not initially written explicitly to target individuals based on race, ethnicity, or economic status, but in practice, they evolved to target people on the basis of race, ethnicity, and economic status.

California and North Carolina carried out the most involuntary sterilizations in the country, with 20,000 and 7,600 sterilization performed, respectively.^{15,16,42} In both states, sterilization laws were utilized to disproportionately target people based on their race and ethnicity. In California, Mexican Americans made up 4% of the population but accounted for 7-8% of the forced sterilizations.¹⁵ In North Carolina, Black women accounted for 60% of involuntary sterilizations in the 1960s.^{14,36} North Carolina was also one of the only states to increase the number of sterilizations performed after World War II.^{22,23} Some scholars speculated that the increase in sterilizations of Black women during this time may be due in part to the growing civil rights movement.^{14,36} The North Carolina sterilization program was also unique because it allowed welfare officials to report people as candidates for sterilization.^{23,36,42} Welfare departments were reluctant to use welfare relief to support Black families, whom they saw as a burden to the system, and targeted Black women for sterilization in order to reduce their ability to apply for additional welfare benefits.^{23,36,42}

ASHG was Silent when Genetics was Misused to Justify Social Harms

Social Harms

In the 1960s and 1970s, genetics was used to justify social issues such as the belief in race-based differences in intelligence, negative stereotypes about individuals with XYY syndrome, and discrimination against Black people based on sickle cell status. While this list is not exhaustive of all instances of genetics being used to justify harms during this time, these examples highlight the societal impact of this line of thinking.

Genetic Basis for Intelligence Differences Between Racialized Groups

The Civil Rights Act of 1964 prohibited discrimination on the basis of sex, race, color, religion, or national origin in decisions regarding hiring, firing, and public accommodations.⁴³ As this Act provided legal protection against discrimination for historically minoritized groups, opponents of this legislation were finding ways to further perpetuate social hierarchies that disadvantaged those groups. One instance of this was by reigniting debates surrounding the heritability of intelligence, with some scientists asserting that Black people were intellectually inferior due to their genetics.

One notable scientist pushing forward the idea of intellectual heritability was physicist William Shockley. Shockley was vocal about his beliefs that “bad heredity” caused Black people to possess “intellectual and social deficits.”⁴⁴ His claims were based on anecdotal evidence and eugenic ideals, and he conducted little actual scientific research to support his theories.⁴⁵ Shockley’s claims were highly criticized and labeled as racist, but this did not stop him from seeking support and funding for his work.⁴⁵ During the 1966 National Academy of Sciences (NAS) meeting, Shockley continued to advocate for his views and asked NAS to provide support for his work.⁴⁴ NAS was conflicted about supporting him because, while they supported free inquiry, they stated that NAS’ recognition of Shockley’s research could be “destructively exploited by racists.”⁴⁴

In 1969, Arthur Jensen, a psychologist, published his paper “How much can we boost IQ and scholastic achievement?”^{44,46} Jensen’s paper concluded that the IQ scores of Black people were lower than those of White people and asserted that interventions aimed at raising IQ, such as Head Start programs, were “fruitless” due to the heritability of intelligence.⁴⁶ These findings were met with substantial criticism given the paper’s racist undertones and questionable methodology. However, segregationists agreed with Jensen’s findings and used his work to support their efforts to resegregate schools.⁴⁷ In 1970, Jensen testified before Congress alongside a group of people who opposed school integration.⁴⁷ He claimed that integration would place Black children in “normal” classes (i.e., classes with White children) rather than special classes for “the retarded,” and cautioned that teachers might “treat [Black students] like the average white child.”⁴⁷

The most vocal scientists, including Shockley and Jensen, who promoted the fallacy that genetics determined differences in intelligence between racialized groups did not have any background or training in genetics. While Shockley and Jensen’s assertions were met with criticism within the genetics community, prominent geneticists and ASHG were hesitant to publicly challenge them. During the 1966 NAS meeting, James Neel was asked to confront Shockley, but he refused because he thought it would be a spectacle that would “do little to further science.”⁴⁴ However in 1967, NAS, led by Neel, released a statement refuting Shockley’s claims.⁴⁴ ASHG decided not to release statements refuting Shockley and Jensen’s claims, based on internal policies against publicly addressing controversial issues. It was not

until 1974 that ASHG recognized the issue during its annual meeting at a panel, “The Utility of Heritability Estimates in Human Genetics.”⁴⁶ The panel discussed both sides of whether the heritability of IQ was based on race, and Jensen was one of the speakers.⁴⁶

Genetic Basis for Criminality

In 1965, Patricia Jacobs, a geneticist, published her paper “Aggressive behaviour, mental subnormality and the XYY male,” which examined the prevalence of males with XYY syndrome in criminal institutions.^{48,49} XYY syndrome is a rare chromosomal disorder in males where they have two Y chromosomes instead of one.⁵⁰ Males with XYY syndrome may exhibit learning disabilities and behavioral problems, such as impulsivity, but they are not more prone to aggression.⁵⁰ Jacobs concluded that there may be an overrepresentation of males with XYY syndrome in penal institutions and that this overrepresentation may be due to an association between the XYY genotype and antisocial behavior.⁴⁸ Even though the study found that males with XYY syndrome were less violent and less aggressive compared to other institutionalized individuals, the paper’s title suggested the opposite.^{48,51} Therefore the findings were sensationalized and used to support arguments that there was a genetic basis for criminality. Jacobs later admitted during her 1982 ASHG Allan Award address that she should not have used the wording she used in the title of the paper.⁴⁸

In the subsequent years, Jacob’s paper provided the supposed grounds for more research to screen for the prevalence of males with XYY syndrome in the general public and detention centers. Some of this research had serious ethical problems regarding informed consent. For instance, in the 1970s, researchers in Maryland conducted XYY screenings on Black youths.⁵² The primary study sites were juvenile detention centers and a Johns Hopkins daycare center where Black youths made up 75% and 95% of the population respectively.⁵² The Johns Hopkins study sought to examine the prevalence of males with XYY syndrome in the general population by testing leftover samples from anemia tests.⁵² However, the researchers did not get consent from the children’s parents nor inform them that their children’s samples were going to be used in the study.⁵²⁻⁵⁴ The juvenile detention center studies sought to confirm Jacobs’ findings that there was an over-representation of males with XYY syndrome in detention centers.⁵² While researchers did provide the boys’ guardians with consent forms, they did not adequately explain why XYY screening was being conducted, the theories surrounding males with XYY syndrome and criminality, or the potential legal ramifications of screening results.⁵² There were also concerns that parents were coerced into signing the consent forms, that blood draws were being performed by untrained psychology students, and that test results were being provided to juvenile correctional agencies as evidence of participants’ propensity for criminality.^{52,54}

The American Civil Liberties Union (ACLU) filed complaints against Johns Hopkins University and the National Institute of Mental Health’s Center for Studies of Crime and Delinquency due to the potential for the screening results to be used unfairly in criminal cases.⁵²⁻⁵⁴ The studies were stopped for almost two months while researchers developed consent forms that adequately informed participants’ guardians about the reasoning behind the research and how samples would be obtained.⁵⁴ However, the consent forms did not guarantee that test results would be confidential, so results could still be used in a court of law.⁵⁴ Also, participants whose samples were already collected for XYY screening were not notified that their rights may have been violated.⁵⁴ The fallout from these studies further drew a wedge between the Black community and medical institutions.

Genetic Basis for Discrimination

Sickle cell disease (SCD) is a group of genetic red blood cell disorders in which abnormal hemoglobin formation causes red blood cells to develop a sickle (i.e., c-shaped) shape.⁵⁵ These cells die quickly and can cause clots in small arteries, which leads to frequent low red blood cell counts, pain, and various other health complications.⁵⁵ Individuals who inherit genetic variants that encode at least one abnormal sickle hemoglobin and another abnormal hemoglobin from each of their parents have SCD; however, individuals who inherit the sickle hemoglobin variant from one parent and “normal” hemoglobin for the other parent have sickle cell trait (SCT). People with SCT do not typically experience the health concerns associated with SCD.⁵⁵ SCD was discovered in 1904, but its molecular basis was not fully understood until 1958.^{56,57} SCD and SCT occur predominantly in people of primarily African ancestry, but also occur in other populations in the United States and globally.⁵⁸ During the height of struggles for human and civil rights across the United States in the 1960s and 1970s, SCD was used to promote racist propaganda.^{56,59,60}

Misunderstandings about the genetic nature of SCD and its prevalence among Black people were used to discourage interracial relationships out of fears that Black people would pass horrific diseases to their children.^{56,59,61} This fear was further perpetuated by the misassumption that SCD and SCT were interchangeable. This misunderstanding led to individuals with SCT being discriminated against and denied health and life insurance, employment opportunities, and acceptance into the armed services.^{59,60,62} Linus Pauling, the chemist who determined that SCD was associated with a change in hemoglobin, advocated that all individuals with SCT should have their foreheads branded to mark their status and to be held to marriage and procreation restrictions.^{20,63}

In 1972, the National Sickle Cell Disease Control Act was passed, which established limited funding for SCD screening, research, and training.^{56,60} This legislation laid the groundwork for states to develop their own SCD screening laws. However, these laws were developed based on false assumptions and caused more harm than good. James Bowman (ASHG Social Issues Committee member, 1975-1978), Director of the Comprehensive Sickle Cell Center at the University of Chicago (1973-1984), and advocate for individuals with sickle cell disease, classified SCD screening laws as “more harmful than beneficial,” as they could “revive many of the past misadventures and racism of eugenics movements,” and provide “inaccurate, misleading, politically motivated propaganda.”⁶⁴ The belief that SCD affects only Black people led to wording in policies that implicitly targeted Black people, such as screening only being applicable for “urban” schoolchildren and all persons “not of the Caucasian, Indian, or Oriental races.”^{59,60,62} Lawmakers used stereotypes about Black people being carriers of venereal diseases as the basis for laws that treated SCD as a communicable disease.^{59,62} These laws also exploited the misconception that SCD and SCT were interchangeable by utilizing tests that did not distinguish between SCD and SCT.⁶² These laws also left Black people open to further discrimination because they did not include protections like test result confidentiality, access to genetic counseling, and guaranteed access to health care.⁶² However, some state legislatures recognized the potential for discrimination and passed laws to prohibit discrimination based on SCT status.⁶⁵

ASHG’s Response to Social Harms

As debates surrounding social issues used genetics and heritability to support the perpetration of harm, ASHG was largely silent on these matters. While ASHG had a Social Issues Committee (SIC) and presidential addresses touched on the XY controversy, these platforms did not adequately address the impact the misrepresentation of genetics research was having on society.

ASHG's Social Issues Committee

In the wake of the debates about race and intelligence, during the 1964 business meeting, ASHG leadership discussed whether it should release a statement in response to Shockley's claims about race and IQ and the "biological aspects of racial questions."⁴⁴ ASHG decided not to release a statement at that point due to concerns that there would not be a consensus among the members and that there was a lack of unbiased literature about race and intelligence.⁴⁴ While ASHG did not release a statement about the genetic basis of intelligence, in 1967, prominent ASHG leaders (James Neel, Curt Stern, and James Crow) wrote an article in *Science* that addressed the heritability of complex traits, such as intelligence, and the interaction of genes with the environment.⁴⁴ However as genetics increasingly became a basis for social and political matters, ASHG established the SIC in 1967 to address these issues.

The SIC's initial purpose was to "explore legal-social aspects related to human genetics."⁴⁴ The group decided not to address the race and intelligence debate, instead focusing on issues related to the technoscientific developments in human genetics such as genetic screening and prenatal diagnosis.⁴⁴ This decision was due to ASHG leaders' frustration with being excluded from conversations surrounding the development of state-mandated neonatal screenings for Phenylketonuria (PKU).⁴⁴ The SIC wanted to ensure that geneticists were consulted prior to the widespread implementation of medical or public health policies that utilized genetic technologies. Therefore, the committee's first initiative was to work behind the scenes to help improve PKU screening programs.⁴⁴ The initial decision to avoid participating in one of the biggest debates in genetics and society set the stage for future SIC initiatives and policies. In order to avoid taking a stance on controversial ethical, scientific, and policy issues, the SIC decided not to issue public policy prescriptions or position statements on behalf of ASHG.⁴⁴ The committee's initial mandate was not extended after the completion of the PKU initiative in 1968.

The SIC was reinstated in 1969 in response to Jensen's paper on race and intelligence. However, while the members were concerned with Jensen's methodology and findings, the committee did not release a statement refuting the claims in his paper because they "could not categorically state that Jensen is wrong."⁴⁴ Instead, members were asked to write articles for *Scientific American* and the *Harvard Educational Review* challenging Jensen's findings.⁴⁴ Even though the SIC was reinstated in response to the misuse of genetics to promote social harms, they still refused to issue direct statements about these harms and opted to address them indirectly through symposia about issues surrounding genetic screening and diagnosis. This silence was particularly troubling considering how these findings were being used by groups that supported undoing parts of the Civil Rights Act.⁴⁵

This intentional silence surrounding the use of genetics as a basis for racist ideologies frustrated members of the SIC and ASHG.⁴⁴ In 1972, Robert Murray, an SIC member who was particularly troubled by the ulterior motives of SCD screening, voiced his frustration with the SIC's inaction in a letter to ASHG's president and encouraged ASHG to take a public stand.⁴⁴ Members of ASHG wanted the SIC to engage the membership in discussions surrounding members' concerns and issue public statements reflecting the majority voice of ASHG. During the 1973 Annual Meeting, the SIC was revamped to reflect members' desire for a more active response to societal issues.

ASHG's Response to XYY Research

John Hamerton (ASHG President, 1975) used his Presidential Address to address criticism of the validity of XYY studies.⁶⁶ During his address, Hamerton laid out the scientific evidence that males with XYY syndrome may have a psychopathology; however in his conclusion, he acknowledged that there was limited evidence to support the view that the psychopathology of males with XYY syndrome could be classified as deviant.⁶⁶ Hamerton's address did little to refute the concerns surrounding the social

ramifications and research practices of XYY research. He also did not address how the misconception that males with XYY syndrome were inherently deviant contributed to the stigmatization of males with XYY syndrome and further fueled arguments about the genetic basis of criminality.^{51,66} Hamerton also failed to address whether the scientific benefit of XYY research outweighed the societal harm. Hamerton's remarks, and their failure to address societal harms, were especially harmful as ASHG's meeting that year took place in Baltimore, where XYY studies had serious ethics violations. Additionally, he specifically referenced the work of Saleem Shah and Digamber Borgaonkar who were the funder and project director of the ethically-fraught XYY studies.^{52,53} While Hamerton's address broke from ASHG's pattern of refraining from addressing controversial topics, he still failed to address the social impact of the genetics research.

James Bowman (1923-2011)



James Bowman was a fervent advocate against sickle cell disease misinformation and used his platform to call out sickle cell misinformation within the Black community and on a national scale. In the 1970s, Black Panther representatives from Chicago approached him to discuss their sickle cell screening program in the Chicago public schools.⁷⁰ Bowman did not agree with components of it because parents were provided with misinformation about their children's sickle cell status.^{70,71} The screening tests utilized in this program did not differentiate between sickle cell disease and sickle cell trait, and screening administrators did not understand how to interpret test results correctly.^{70,71} From that interaction with the Black Panthers, Bowman "started [his] crusade" against sickle cell misinformation.⁷⁰ He continued to call out instances of misinformation, including a National Institutes of Health brochure that did not make a distinction between sickle cell disease and sickle cell trait; policies that disqualified people with sickle cell trait from insurance, athletics, and job opportunities; and fake charities and cures that exploited the Black community's fear of sickle cell.⁷⁰

From 1973 to 1984, Bowman directed the Comprehensive Sickle Cell Center of the University of Chicago, which was dedicated to furthering patient care, research, and education surrounding sickle cell disease.^{64,71} Between 1972 and 1975, Bowman served on six national committees concerned with sickle cell-related matters, including two federal review committees that evaluated sickle cell screening, education, and laboratory diagnostic techniques.^{64,71} Bowman was also a member of ASHG's Social Issues Committee from 1975 to 1978.⁷⁰ Bowman published more than 90 research studies, including the book *Genetic Variation and Disorders in Peoples of African Origin*, which he co-authored with Robert Murray.⁶⁴

Robert Murray (1931-2022)

Robert Murray was an advocate for pediatric sickle cell disease education and research. Murray was one of the initial members of ASHG's Social Issues Committee.⁴⁴ He took a vocal stance against the committee's silence in the face of misguided sickle cell screening and counseling policies. In a letter to ASHG's president in 1972 he voiced his concerns, stating, "I feel this is a very crucial year for the Society because it has an opportunity to make its presence felt in the crisis in screening and counseling that is suddenly upon us. If the events surrounding sickle cell and Tay-Sachs screening and counseling should pervert the attempts of people who want to do good through them, we must share part of the responsibility unless we take an affirmative stand and allow our views to be known to the public at large."⁴⁴ Murray also opposed mandatory sickle cell screening laws for children due to concerns surrounding issues of privacy and how these laws would disproportionately be applied to Black children.⁶⁷ He did support making the screening voluntary as long as parents were properly informed about the implication of screening results.⁶⁷ Murray also promoted the importance of educating patients about the realities of sickle cell disease. When describing his interactions with patients, Murray stated, "Sometimes we have to allay fears that having a sickle cell child means God is angry. We tell them that God doesn't punish people through their children, that in many ways our genes are an accident of nature. Usually, couples come to us scared and leave somewhat relieved."⁶⁸

Murray was a member of Howard University's faculty for 42 years, where he served as chair of the Graduate Department of Genetics and Human Genetics.⁶⁹ Over the course of his career he authored and co-authored over 80 publications, including the book *Genetic Variation and Disorders in Peoples of African Origin*, which he co-authored with James Bowman.⁶⁹

ASHG's Evolving Role to Advance Ethical and Legal Protections

Ethical Considerations Surrounding Genetics Research

Starting in the early 1960s, codes of conduct were developed to provide human subjects protection to people participating in scientific research by requiring researchers to consider the ethics surrounding their studies.⁷²⁻⁷⁵ As genetics research became more advanced and more sensitive information could be gleaned from genetic testing, there were increased calls for people conducting genetics studies to address the ethical implications of their research methods and findings. Ethical concerns surrounding human genetics research included insufficient informed consent due to participants' lack of awareness about the full breadth of studies their samples would be used for and ambiguity about the potential benefits and detriments of study findings. Other concerns included insufficient privacy safeguards and lack of cultural sensitivity. Two projects from the 1990s, the Human Genome Diversity Project and Arizona State University's Diabetes Project, were met with widespread criticism due to these ethical concerns.

The Human Genome Diversity Project

The Human Genome Diversity Project (HGDP), a project complementary to the Human Genome Project, was led by Luigi Luca Cavalli-Sforza (ASHG President, 1989) and aimed to create a database of genetic information about the world's diverse human populations in an attempt to improve understanding of the full scope of human genetic variation.⁷⁶⁻⁷⁸ In 1994, the U.S. National Research Council (NRC) of the National Academy of Sciences convened a committee to review ethical concerns surrounding the HGDP's methods and purpose.⁷⁸ HGDP's opponents believed that findings could be manipulated to further perpetuate scientific racism by creating new constructs for racial and ethnic superiority.^{39,76-78} HGDP's supporters believed the project would not contribute to scientific racism because the findings could be used to refute claims of racial genetic superiority by proving there is no significant genetic basis for race.⁷⁷ In addition to the concerns about the interpretation of the HGDP findings, opponents were also apprehensive about the inclusion of Indigenous people as one of the main target populations.

The HGDP planned to recruit participants from isolated Indigenous communities due to beliefs that there would be little admixture in those groups.⁷⁹ However, the project's organizers failed to consider how Indigenous groups would receive this work, given a history of mistrust due to colonialization and exploitation. Some Indigenous groups see research as a form of "biopiracy" where researchers benefit from the information generated from Indigenous groups but where the Indigenous groups do not see those same benefits.⁷⁶ In 1995, a coalition of Indigenous groups in the western hemisphere released a declaration opposing the HGDP due to concerns that their genetic information would be patented and used for commercial, scientific, and military purposes.⁸⁰ While the organizers of the HGDP affirmed that study samples would not be used for commercial purposes, there were still questions about the purpose of the project.^{76,79} There was doubt that the findings would provide biomedical benefits to participants because researchers were not collecting medical histories or phenotypes.^{76,79} Also in 1995, representatives from Indigenous organizations met with HGDP's organizers to discuss project goals and objectives, but the conversations were not fruitful, due to representatives' and organizers' inability to come to an understanding about a mutually beneficial purpose.^{77,79} In 1997, the NRC completed its review and decided the HGDP could proceed but needed to address its ethical issues.^{76,78} However, the full text of the NRC decision was vague, and members of Indigenous groups felt that while the committee's decision addressed ethical concerns surrounding informed consent and sample storage, it failed to address concerns surrounding the purpose of the project.^{76,78,79}

Havasupai Tribe v. Arizona Board of Regents

Between 1990 and 1994 researchers from Arizona State University (ASU) collected DNA samples from members of the Havasupai tribe as part of ASU's Diabetes Project.⁸¹ The Havasupai tribe members were told that their DNA samples would be used to examine genetic links to type II diabetes, which Havasupai adults had higher-than-average rates of.⁸¹⁻⁸⁵ The study was unable to find a genetic link to type II diabetes. Despite not getting participants' consent for additional testing, researchers used the samples for studies on schizophrenia, migration, and inbreeding.⁸¹⁻⁸⁵ These studies showed a lack of cultural awareness because they touched on topics that were taboo among the Havasupai, such as mental health, migration, and 'intermarriage.'⁸¹⁻⁸⁵

In 2004, the Havasupai Tribe filed a lawsuit against the Arizona Board of Regents over the misuse of their genetic material and the lack of complete informed consent.⁸¹ Study participants stated that they would not have participated in the study if they knew that their genetic material would have been used for non-diabetes research.⁸¹ Participants were especially concerned with their genetic materials being

used in other studies given that the findings of those studies could contradict tribal traditional stories, threaten claims to land, and further perpetuate negative stereotypes about Indigenous peoples.^{81–85} In 2010, the Havasupai Tribe received a \$700,000 settlement, which included the return of the DNA samples collected by researchers.^{81–85} The return of DNA samples was a culturally significant part of the settlement because some Indigenous people view DNA as a sacred part of one's personhood.⁸¹

ASHG's Evolution in Advocating for the Ethical and Legal Protection of Genetic Information

ASHG Response to Ethical Considerations in Genetics Research

Until the early 1970s, ASHG took the position to not release public statements or guidance about social issues involving genetics. However, after the SIC was revamped in 1973, ASHG took a more active role in bringing attention to ethical issues in genetics. The SIC took a stance against gender-screening requirements in international athletic competitions and regulations that restricted Title X-funded clinics from offering abortion as an option for family planning.^{86,87} The SIC also examined the need for guidance on issues such as genetic testing in adoption candidates, the use of genetic information by law enforcement, and the use of patient samples for commercial purposes.^{86,87}

While the revamped SIC took a vocal stance on a variety of issues, ASHG still did not respond to every pressing issue of the time. ASHG was reluctant to take a strong stance about race and intelligence. In 1994, Richard Herrnstein and Charles Murray published *The Bell Curve*, which continued to promote the fallacy that genetics determined differences in intelligence and social mobility between racialized groups.⁸ ASHG did not endorse a statement from the Ethical, Legal, and Social Implications Workgroup of the National Advisory Council for Human Genome Research refuting claims made in *The Bell Curve*, stating there was insufficient understanding of the methods used to make these claims.^{77,88} *AJHG* eventually published the statement several months after it was released.⁸⁹ However, in 2007, when James Watson expressed similar sentiments to those expressed in *The Bell Curve*, ASHG released a statement after he apologized calling his comments “tragically misguided and without scientific foundation.”⁹⁰ ASHG also did not seem to engage in HGDP conversations. However, Wylie Burke (ASHG President, 2007) and Roderick McInnes (ASHG President, 2010), addressed the Havasupai incident in their presidential addresses.^{91,92} Burke mentioned the Havasupai tribe as an example of group harm and an example of “legitimate concerns about how genetic research will be conducted and interpreted.”⁹² In his address, McInnes mentioned the importance of geneticists being culturally sensitive to the populations they are studying in order to avoid instilling “a sense of mistrust, stigmatization, or weakened political authority,” in populations that are participating in research.^{91,93} He used the Havasupai case as an example of what happens when that is not the case and how genetic research could be stigmatizing to certain populations.⁹¹

ASHG's Response to Legal Considerations in Genetics Research

In the early 1990s, as the Human Genome Project offered the promise of unprecedented insights into human genetics and the availability of genetic testing increased, there were concerns about how an individual's genetic information could be utilized when making insurance eligibility determinations and hiring decisions. These concerns also contributed to people's apprehension about getting recommended genetic testing and participating in genetics research⁹⁴ and put providers in a difficult situation due to their dual accountability to their patients and insurance companies.⁹⁵ In light of these issues, ASHG advocated for legislation that prevented discrimination based on genetic information obtained in clinical and research settings.

In 1993 ASHG, in conjunction with the Council of Medical Genetics Organizations, wrote a letter to Hillary Clinton about the importance of including regulations prohibiting genetic discrimination in universal health care proposals.⁹⁶ In 1995, ASHG's Ad Hoc Committee on Insurance Issues in Genetic Testing released a background statement that reviewed how genetic testing results could be used to determine insurance eligibility.⁹⁵ Also, in 1995 the first version of the Genetic Information Nondiscrimination Act (GINA) was introduced in Congress. GINA protects individuals from undergoing employer- and health insurer-required genetic testing, and it prevents employers and health insurance companies from making determinations based on an individual's genetic information.⁹⁷ ASHG was a key supporter and advocate for this legislation throughout its many iterations and reintroductions in Congress.⁹⁷⁻⁹⁹ This law applies to the genetic information of individuals and their families that is obtained for clinical and research purposes.⁹⁴

In 2008, GINA was signed into law; however, legislation has since been introduced to weaken its protections.^{94,100} In 2017, the Preserving Employee Wellness Programs Act (H.R.1313) was introduced in Congress, which would allow employers to coerce their employees into disclosing personal and familial health and genetic information and undergoing genetic testing.¹⁰⁰ In response to this proposed legislation, ASHG asked members to sign a letter opposing the bill and encouraged members to contact their representatives and spread awareness of this bill to their personal and professional circles.¹⁰⁰ The Preserving Employee Wellness Programs Act (H.R.1313) did not pass. ASHG understood the potential for individuals to be discriminated against based on their genetic information and preemptively advocated for legislation that would prevent this from happening. Currently, ASHG supports legislation, domestically and internationally, that prevents discrimination based on genetic information and advocates for stronger protections in existing genetic non-discrimination legislation.

Frank Dukepoo (1943-1999)

Frank Dukepoo was an advocate for the protection of Indigenous people in genetic research. He was prominent in providing his perspective as a Hopi and as a geneticist on the Human Genome Diversity Project (HGDP).^{79,101,102} Dukepoo authored several articles and attended various meetings with HGDP organizers to express concerns Indigenous communities had about the HGDP.^{79,101,102} Within his articles, he provided historical and cultural contexts to explain why members of Indigenous communities would have objections to the HGDP.^{79,101,102} He also highlighted individual tribe efforts to ensure they would have more autonomy and control over research in their communities, such as developing protocols for deciding which research studies to participate in.¹⁰² Dukepoo also encouraged continued conversations about the ethical considerations of research projects to ensure that science does not harm minoritized groups. In an article reviewing the impact of research on Indigenous communities he stated, “Within Native American communities there is almost unanimous agreement that researchers who engage in ethnic studies should be knowledgeable of the social, political, and cultural context of the research they propose and should be aware of potential racist implications and racial biases in study designs since results might contribute to stereotyping, discrimination, and labeling.”¹⁰¹

Along with his advocacy for research protections, Dukepoo was an advocate for Indigenous student education. Based on his personal experience struggling to navigate the transition to college, Dukepoo understood the unique challenges Indigenous students faced when entering higher education.^{103,104} During his time at the National Science Foundation he led a program to encourage Indigenous students to stay in school. He also founded the Society for Advancement of Chicanos and Native Americans in Science, the American Indian Science and Engineering Society, and the National Native American Honor Society which provides support to Indigenous students throughout their education.^{103,104}

ASHG Strives for a More Equitable and Just Future

The Field of Genetics Progresses Towards Inclusivity

In the early 2000s, the Human Genome Project helped confirm there was no scientific or genetic basis for biological race in humans.¹⁰⁵ Despite these and other corroborating findings, some scientists continued to promote the idea that significant differences between races are due to genetics.^{5,106,107} These claims were met with widespread criticism, and prominent geneticists, including Georgia Dunston and Francis Collins, called for conversations about more nuanced ways to discuss population-based genetic variation.^{106,108–110} While the findings from the Human Genome Project surrounding race and genetics were a point of progress, the project also highlighted the need for more diversity among participants of genomics research.

Most participants in genetics and genomic studies are of European ancestry.^{83,111,112} It is estimated that 13.5% of genomic study participants are of non-European ancestry, with 10% of them of Asian ancestry and 3.5% of African, Hispanic, or non-specified ancestry.¹¹¹ In part, this may be due to mistrust and untrustworthiness of scientific research.^{113,114} Historically, underrepresented communities had very little agency over their participation in research.^{113,114} They were often the subjects of research, and their needs and humanity were disregarded in the process. Therefore, some members of these communities saw participation in scientific research as an exploitative endeavor without benefits. The mistrust resulting from unethical research or oppressive lived experiences made it more difficult, but not impossible, to engage minoritized groups in studies. This lack of diversity in genetics and genomics research extends into the workforce as well.

With an intent to address the need for diversity, initiatives were developed to engage people from historically excluded groups in genetics and genomics research:

- The National Human Genome Center (NHGC) at Howard University was established in 2001 with a mission to conduct and teach genetics and genomics research that centers on diseases common among African Americans and other populations within the African Diaspora.^{108,115} The Center's location at Howard University, a Historically Black College and University, made it uniquely situated to engage more Black participants and researchers.
- To engage Indigenous communities in genetics research, the [Summer Internship for Indigenous Peoples in Genomics \(SING\)](#) was established to educate and engage communities about genomics and discuss its uses and misuses.
- The National Institutes of Health has also funded initiatives and research programs, such as [Human Heredity and Health in Africa \(H3Africa\)](#) and [All of Us](#), which aim to engage participants, and, in the case of H3Africa, researchers, from historically excluded groups in genetics research.⁸³

These initiatives represent a fraction of the efforts to make genetics research participation and the workforce more inclusive.

ASHG's Commitment to Diversity, Equity, and Inclusion

While the scientific findings of the Human Genome Project made clear the falsity of claims of racial superiority due to superior genetics, societal factions in the public sphere have continued to misuse genetics to advance concepts of racial hierarchy.¹¹⁶ In response to White supremacists' continued attempts to use genetics to rationalize their beliefs, ASHG released statements refuting attempts to "misuse genetics to feed racist ideologies."^{117,118} In both the [2018](#) and [2020](#) statements, ASHG strongly denounced these false "theories," provided the genetic evidence to debunk this thinking, and committed to continue using its platform to call out scientific racism.^{117,118} On top of being more vocal about instances of harm, ASHG also established Diversity, Equity, and Inclusion (DEI) initiatives that aim to increase diversity in the genetics workforce and research participation.

In January 2020, ASHG released a [Diversity and Inclusion Policy Statement](#) that articulated its first specific commitment to advancing diversity and inclusion within ASHG and in the broader genetics and genomics community.^{119,120} To operationalize this policy, the ASHG Board developed a DEI Task Force. The main objective of the Task Force is to address diversity and inclusion in ASHG's membership and leadership, in the genetics and genomics workforce, and in research participation.¹¹⁹ The Task Force developed, and the Board approved, a comprehensive [action plan](#) that sets aspirational and actionable activities that ASHG can implement to further its DEI goals.¹²¹ The initial actions focused primarily on

expanding diversity and inclusion in the workforce and within research studies, and cultivating an inclusive environment among ASHG volunteer leadership and membership.¹²² ASHG's commitment to increasing workforce inclusion is evidenced by its [Human Genetics Scholars](#) and [Human Genetics and Genomics Workforce Diversity](#) initiatives.^{123–125} The Human Genetics Scholars initiative provides training and mentorship to U.S. trainees and early career scientists from underrepresented backgrounds.¹²⁵ The Human Genetics and Genomics Workforce Diversity initiative is a collaboration between ASHG, the National Human Genome Research Institute (NHGRI), and other leading genetics organizations to assess the demographic landscape of the U.S. human genetics and genomics workforce and develop recommendations for future collective action to enhance diversity and inclusion.¹²³ To address the issue of diversity among genetics research participants, ASHG released a [perspective article](#) that provided special considerations for engaging vulnerable populations in genetics research.¹¹³

The Society is also working to ensure its major scientific pillars increase consistent attention to topics of diversity, equity, and inclusion in all facets of the field. As has been chronicled in this report for the Society's early years, the scientific record is a powerful mechanism to communicate discovery, but in doing so it also communicates underlying values and beliefs. New ASHG initiatives require Annual Meeting symposium submissions to consider both topical and presenter diversity; new educational sessions are dedicated to diverse, equitable and inclusive scientific topics; and several recent statements and professional research practice guidelines center on ethical and effective engagement of diverse or vulnerable populations. Similarly, ASHG journal editors have established DEI as a major consideration and have clarified their expectations for documentation that ethical standards have been upheld when engaging diverse populations.

In 2021, in response to Board guidance, the DEI Task Force developed, and the Board approved, additional areas of focus with accompanying actions. One area of focus, "acknowledging and documenting a history of past indiscretions linked to racism, eugenics, or other systemic forms of injustice in the field" became the basis for the Facing our History - Building an Equitable Future Initiative.¹²² ASHG has made progress from its early associations with the American eugenics movement and its silence when genetics was being used to justify harms, but the Society recognizes this area as one that needs important, ongoing intentional work to realize long-term change. ASHG advocates for legal protections against genetic discrimination, uses its platform to denounce the misuse of genetics to promote scientific racism, and is making strides to increase diversity within the genetics workforce and research participation. While these are signs of progress, there is still work to be done to achieve an equitable and just future.

Georgia Dunston



Georgia Dunston is a human geneticist whose pioneering work focuses on human genome variation and disease susceptibility for diseases that are common in people of African descent.¹²⁶ Dunston, who was the first Black student in the University of Michigan's Human Genetics department, earned her PhD in 1972. She was a member of Howard University's faculty for 45 years, where she served as Chair of the Department of Microbiology, a graduate faculty member in the Department of Genetics, and the founding director of the National Human Genome Center (NHGC) at Howard University.¹²⁶⁻¹²⁸ Throughout her time at Howard, Dunston fostered research and scholarship at the National Institutes of Health (NIH) through various collaborations and fellowships, including a Visiting Investigator's Program at the National Human Genome Research Institute during the height of the Human Genome Project.^{126,127} Dunston describes her perspective on genetics and human identity as "not motivated by conventional mainstream conversations on human genome variation and differences, but seeks rather to reframe the discussion in ways that provoke new thinking on the emergence of the human genome as the most elegant living information and communication system known to science."¹²⁶

Dunston's cutting edge work at Howard University in human immunogenetics research put the university in a position to receive funding from NIH's Research Centers in Minority Institutions Interdisciplinary Program.^{127,128} This funding enabled the university to develop the necessary infrastructure to establish a human genomics laboratory, which laid the foundation for the development of the NHGC.^{127,128} As founding director of the NHGC, Dunston played a critical role in centering Howard as a key institute for human genetics and genomics research.¹²⁸ The NHGC has served a pivotal role in the trainings and careers of many students and researchers from minoritized groups, a convener for conversations about the human genome and race, and a leader in research on the genetics of diseases common in African Americans and other African Diaspora populations.^{126,127}

Select ASHG Statements, Guidance, and Perspectives

- **1999:** [Opposing Eugenics and Restrictions on Reproductive Freedom](#) - Opposition of coercive efforts to restrict freedom of choice based on known or presumed genetic characteristics of potential parents or the anticipated genetic characteristics, health, or capacities of potential offspring
- **2007:** [Responding to Misguided Beliefs](#) - ASHG's response to James Watson's comments about intellectual inferiority of Africans
- **2010:** [Genetic Ancestry Testing Challenges Identified By American Society Of Human Genetics Task Force](#) - Provides a background on science and potential implications of direct-to-consumer genetic ancestry tests and recommendations for collaboration among academia, industry, and other stakeholders
- **2018:** [ASHG Denounces Attempts to Link Genetics and Racial Supremacy](#) - ASHG's statement denouncing the misuse of genetics to feed racist ideologies
- **2019:** [Prohibiting Genetic Discrimination to Promote Science, Health, and Fairness](#) - Reaffirms ASHG's commitment to advocating for strong legal protections against genetic discrimination
- **2020:** [New Policy Statement Highlights Diversity and Inclusion Goals in Genetics and Genomics Research](#) - Articulates ASHG's commitment to advancing diversity and inclusion within ASHG and in the broader genetics and genomics community
- **2020:** [Advocating for Genetics and Genomics Research to Policymakers](#) – Highlights the importance of advocacy and provides guidelines for how to engage policymakers about the benefits of genetics and genomics research
- **2020:** [Fostering Responsible Research on Ancient DNA](#) - Offers five practical recommendations for researchers of ancient DNA to foster and promote ethical engagement between researchers and communities
- **2020:** [Advancing Diverse Participation in Research with Special Consideration for Vulnerable Populations](#) - Outlines fundamental responsibilities to conduct research in ways that address the distinct needs of vulnerable populations, including Indigenous populations, ethnic and political minorities, and immigrant and refugee communities
- **2020:** [American Society of Human Genetics Statement Regarding Concepts of “Good Genes” and Human Genetics](#) - ASHG's statement denouncing the use of genetics knowledge for social or political ends
- **2022:** [The Importance of Advocacy as a Scientist](#) - Outlines the importance of scientists engaging with politicians to advocate for pro-science policies
- **2022:** [The importance of universal ethical standards in science](#) - Articulates ASHG's expectations that scientists worldwide abide by universal ethical standards for biomedical research and provides updates for ASHG's policies and practices for journal publication and Annual Meeting content
- **2022:** [ASHG Issues New Guidance Addressing Underrepresentation in Genomics Research Through Community Engagement](#) - Guidance on community engagement as a strategy to address underrepresentation in genomics research

Insights for Action

These Insights for Action describe potential actions ASHG could undertake to acknowledge and reckon with past harms and build an equitable future. The insights were developed with input from the Expert Panel and ASHG’s community dialogue session. These insights serve as the basis for potential impactful and measurable short-term and long-term strategies within ASHG. However, appropriate and generative responses to historical harms is an emerging discipline that may give rise to recommendations which go beyond, or obviate, the actions proposed here. These Insights for Action include those that “look back” to acknowledge and reckon with harms and those that “look forward” to build a more equitable human genetics research community.

Reckoning with ASHG’s History: Looking Back

1. First and foremost, the Expert Panel suggests that ASHG should consider issuing an apology for the role that it played in perpetuating harm, and that the apology should address ASHG’s reticence to use its platform to speak out during times when human genetics was used to justify harm against members of minoritized groups. The first step in healing is acknowledging and apologizing for causing harm.
2. This report highlights the importance of knowing history so that issues of the past are not repeated. Thus, ASHG members should have the opportunity to learn more about ASHG’s history, including the contributions to harms and injustices. This should be accomplished by
 - updating the history section of the ASHG website to reflect the findings from this initiative, and
 - building sessions into the annual meeting or other events and programs, on an ongoing basis, to discuss key historical moments, beliefs, and/or figures, and reflect on them as part of sustained efforts to advance diversity, equity, and inclusion within human genetics research moving forward.
3. ASHG should undertake an immediate and serious consideration of whether its Society awards are named for members who were eugenicists and if so, change the names of those awards. As noted in this report, ASHG’s highest Society honor, the Allan Award, is named after a known eugenicist who held disturbing opinions about people with disabilities, and some other awards are named for those believed to have held comparable views. At a minimum, the Society should change the name of the Allan Award and develop vetting processes for naming awards after individuals if it seeks to continue naming awards after people.

Building an Equitable Future: Looking Forward

1. ASHG could consider making a promise to keep vigilant in speaking out—and encouraging members to speak out publicly and through their scientific research communication—against modern attempts to use human genetics to advance racism, assert other forms of “superiority,” or perpetuate discrimination.
2. ASHG could collaborate and engage in meaningful dialogues with groups on whom harms in human genetics research were perpetrated to redress past transgressions and identify meaningful future actions together. These dialogues and meetings could occur on both the levels of communities and academic institutions.

3. Given this report's evidence of the impact of human genetics and genomics on other scientific disciplines and society at large, ASHG could consider how it can best collaborate with organizations in other disciplines to advance equity.
4. During the Community Dialogue, there was heightened interest for ASHG to build policy awareness and advocacy capacity on these issues among members and within ASHG as an organization. ASHG has expanded its policy awareness and advocacy programming as evidenced by the [advocacy resources](#) on its website; the Board of Directors' increasingly active role to speak out on public issues through Society statements; and ASHG's creation of the Government and Public Advocacy Committee to implement the Society's advocacy priorities and activities. ASHG could consider how to increase member awareness about these resources and continue to advance its values through active communication with policymakers, ASHG members, and the larger public.

Appendix 1 - Research and Environmental Scan Search Plan

Background

The Research & Environmental Scan Search Plan is a living document, used to conduct research including an environmental scan (i.e., a search of peer-reviewed, grey, and published literature) to document history of past injustice (e.g., eugenics and racism) as well as progress toward justice in the human genetics field and the Society. The search methodology includes key terms, sources, inclusion and exclusion criteria, Board guidance, and research questions to be addressed.

Research 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?

Inclusion and Exclusion Criteria

Inclusion Criteria

- Timeline: Founding of ASHG (1948) to 2021
 - Key antecedent views or activities that were relevant to the Society's formation can also be included
- Key historical milestones, views, persons, actions, events, examples, statements, and contributors of gross injustice in human genetics and genomics research
- ASHG's past role in generating, disseminating, or promoting harms that have helped contribute to the evolution and institutionalization of racism or other dehumanization of communities
 - Being mindful of differentiating between individual views/actions and ASHG views/actions, while articulating and commenting on any interactions between individuals and the Society
- Significant areas of progress and paradigm shifts toward justice in human genetics and genomics research or ASHG

Exclusion Criteria

- Experiences of injustices solely within the medical field and research areas outside the context of human genetics and genomics
- Injustices with origins outside of the United States
 - The impact of U.S. influences or potentially unjust actions in the international context may be included
 - Acknowledging international issues that significantly impacted U.S. experiences may be included
 - Including U.S. scientists who worked abroad (e.g., U.S.-based genetic scientists who led expeditions on the African continent in the post-WWII period)
- Contemporary issues of injustice
 - Acknowledging present day harms, while maintaining a focus on history

Sources of Information

- Peer-reviewed literature: (e.g., American Journal of Human Genetics)
 - Seminal research
 - Case studies (e.g., sickle cell disease, down syndrome)
 - 2012 - 2017 AJHG Issue Covers
 - *The Bell Curve*
- Grey literature (e.g., 1950 UNESCO statement The Race Question)
 - Reports
 - Muller's papers
 - American Philosophical Association
 - Allan Award Addresses
 - ASHG leadership correspondence
 - Ancestry Taskforce White Paper (2010)
- Published literature
 - Articles
 - Perspective articles
 - Mismeasure of Man
- Curated resources
- Key Figures (e.g., Curt Stern, James V. Neel, Franz J. Kallman)
 - Francis Galton
 - Charles Davenport
 - James Watson
 - H.J. Muller
- ASHG Statements (e.g., Presidential Addresses)
 - Meeting Abstracts
 - Editorials
 - Commentaries
 - Anniversary addresses
- Oral histories/interviews (e.g., Georgia Dunston)
- Key institutions
 - Eugenics Record Office (Cold Spring Harbor)
 - NIH

Relevant Search Terms

- To include 'genetics,' 'gene,' 'genome,' 'DNA,' 'heredity,' 'hereditary,' and 'inborn factors'
- Terms focusing on identifying prejudice and injustice might include 'race,' 'racial,' 'ethnic,' 'ethnicity,' 'disability,' 'inferior,' 'feeble-minded,' 'sterilization,' 'eugenics,' scientific racism, racism, ableism, health disparities (early on discussions), ancestry, intelligence, IQ (bell shaped curve), gay gene, nature/nurture, determinism, genetic determinism, genetic essentialism, biological determinism
- Signature moments in American history or that influenced American history (e.g., Nazism, Jim Crow, etc.)

Methodology

Research and Environmental Scan Search Plan

- Developed the initial draft of the Research and Environmental Scan Search Plan based on parameters from the initiative and Board guidance
- The Search Plan included research questions, inclusion and exclusion criteria, potential sources of information, and relevant search terms
- During the first Expert Panel meeting, the Expert Panel reviewed the draft Search Plan and provide feedback
- The Expert Panel's feedback was incorporated into the final version of the Search Plan

Literature Search

- Resources were identified based on the Search Plan's inclusion and exclusion criteria, potential sources of information, and relevant search terms
- The literature review employed a backward snowballing technique during which new resources were identified based on the references and information (e.g., key terms and figures, events) in the initial set of resources
- The resources for the Environmental Scan included
 - AJHG Presidential Cover Stories
 - ASHG Presidential Addresses
 - ASHG Statements
 - AJHG Perspective Articles
 - Journal articles
 - Web pages (e.g., ASHG website, NHGRI website, internet articles, online collections)
 - Conference papers
 - Presentations
 - Blog posts
 - Books

Appendix 2 – Timeline

Theme 1: ASHG and the American Eugenics Movement

- 1883 ● Francis Galton developed the term eugenics
- 1910 ● Charles Davenport established the Eugenics Record Office at Cold Spring Harbor Laboratory
- 1924 ● The Johnson Restrictive Immigration Act of 1924 was passed, which restricted immigrants from Southern and Eastern Europe and Asia from entering the United States
- 1926 ● The American Eugenics Society (AES) is founded to promote racial betterment and eugenics by educating the general public about the benefits of eugenics programs
- 1929 ● North Carolina passed a law that allowed for the involuntary sterilization of those who were deemed “mentally defective or feeble-minded”
- 1939 ● Eugenics Record Office at Cold Spring Harbor closes
- 1948 ● The American Society of Human Genetics (ASHG) is founded
- 1950 & 1951 ● UNESCO Statements on Race are released and establish that “race is a social construct without biological foundation” - Authored by L.C. Dunn (ASHG President 1961)
- 1953 ● ASHG collaborated with AES and held a joint symposium about genetics and intelligence during the American Association for the Advancement of Science (AAAS) meeting
- 1961 ● Inauguration of the William Allan Memorial Award for Outstanding Work in Human Genetics
- 1972 ● The American Eugenics Society changed its name to the Society for the Study of Social Biology
- 1973 ● North Carolina performed its last state-sponsored eugenic sterilization

Theme 2: ASHG was Silent when Genetics was Misused to Justify Social Harms

- 1965 ● Patricia Jacobs published her paper “Aggressive behaviour, mental subnormality and the XYY male,” which findings were sensationalized to suggest that there was a genetic basis for criminality
- 1967 ● ASHG Social Issues Committee is established
- 1969 ● Arthur Jensen published his paper “How Much Can We Boost IQ and Scholastic Achievement?” which implied that racial differences in intelligence (as measured by IQ) were due to hereditary factors, thus he deemed interventions (e.g., Head Start programs) to improve IQ ineffective
- 1972 ● The National Sickle Cell Disease Control Act was passed, which established limited funding for sickle cell disease screening, research, and training
- 1974 ● During the 1974 ASHG meeting, there was a talk entitled “The Utility of Heritability Estimates in Human Genetics,” to discuss the heritability of IQ based on race - Arthur Jensen was on the panel for this discussion

Theme 3: ASHG's Evolving Role to Advance Ethical and Legal Protections

- 1990 ● The Ethical, Legal, and Social Implications Research Program was developed out of concerns about the implications of the Human Genome Project
- 1993 ● ASHG, under the leadership of President Janet Rowley, wrote a letter Hillary Clinton about the need for incorporating rules prohibiting genetic discrimination into the universal health care proposals being drafted at that time
- 1994 ● Richard Herrnstein and Charles Murray published *The Bell Curve*, which promoted that "genetics determined intelligence and social mobility in American society and those genetics caused African Americans and European Americans to have different IQ scores"
- 1994 ● The U.S. National Research Council of the National Academy of Sciences convened a committee to study the feasibility and the ethics of the Human Genome Diversity Project (HGDP) - L. L. Cavalli-Sforza (ASHG President 1989) was the director of the HGDP
- 1995 ● ASHG's Ad Hoc Committee on Genetic Testing/Insurance Issues released a background statement about genetic testing and insurance
- 1995 ● The first version of the Genetic Information Nondiscrimination Act (GINA) was introduced in Congress
- 1997 ● The U.S. National Research Council of the National Academy of Sciences recommended that the HGDP could proceed, but needed to pay attention to informed consent and related ethical issues
- 2001 ● ASHG Board of Directors released a statement in support of GINA
- 2008 ● Genetic Information Nondiscrimination Act (GINA) became law
- 2010 ● The Havasupai Tribe won a settlement against Arizona State University for using Havasupai samples without complete informed consent. The settlement included \$700,000 in direct compensation and funds for a tribal medical clinic and school. Additionally, ASU had to return the samples to the Havasupai Tribe.

Theme 4: ASHG Strives for a More Equitable and Just Future

- 2000 ● A working draft of the human genome helped confirm that there was no scientific or genetic basis for race
- 2001 ● The National Human Genome Center at Howard University was established
- 2003 ● The National Human Genome Center at Howard University held a series of meetings titled "Human Genome Variation and 'Race'" during which experts in sociology, anthropology, history, and genetics discussed whether "race" should be used as a construct for genetic variation
- 2018 ● ASHG released a statement denouncing attempts to link genetics and racial hierarchy
- 2020 ● ASHG released a policy statement that guides its commitment to advance Diversity and Inclusion within ASHG and in the broader genetics and genomics community

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