Received: 8 June 2020 | Revised: 4 September 2020 | Accepted: 19 September 2020
DOI: 10.1002/ajmg.a.61899

EDITORIAL

AMERICAN JOURNAL OF medical genetics PART A WILEY

Diversity, inclusion and equity in medical genetics: The time is now

"…I am convinced that men hate each other because they fear each other. They fear each other because they don't know each other and they don't know each other because they don't communicate with each other.…"—Reverend Martin Luther King, Jr. (Quotation from a speech at Cornell College, Mount Vernon, IA, October 15, 1962).

1 | INTRODUCTION

All of our lives have been disrupted, in some ways permanently by the COVID-19 pandemic. In this evolving saga, the effects of the pandemic have had disproportionate impact on the health and employment of persons of color, particularly African- and Latino-Americans (US Centers for Disease Control and Prevention, 2020; Webb Hooper et al., 2020). Then the death of George Floyd at the hands of police in Minneapolis became a rallying cry and lit a sense of outrage among people of all backgrounds. People across the country have taken to the streets to demonstrate and to bear witness. The broad recognition that enforcement of the law is applied unequally, and that justice is not blind, has been a painful but necessary step toward change. To transform this moment into a movement and lasting effects on society will take more. In this era, each of us has a responsibility to ask the question "What can I do?" Now the work begins.

2 | ACMG AND ASHG DIVERSITY BREAKFASTS

Both of us have been involved in organizing, leading, and participating in diversity events at the annual meetings of the American College of Medical Genetics (ACMG) since 2017, and the American Society of Human Genetics (ASHG) since 2014. The goals of these events is to welcome meeting attendees who wish to increase the diversity of the genetics workforce, and to provide a forum to discuss topics related to equity, diversity, and inclusion (EDI). Attendees have included clinical geneticists, laboratory geneticists, and genetic counselors from all career stages—from senior leaders in the field to trainees and students. With many organizations reviewing their diversity efforts, or beginning programs for the first time, we wanted to share some of the lessons learned, and some of the resources we have used to facilitate discussions about EDI.

3 | INTRODUCTION AND DEFINITIONS

It is helpful to open the session by acknowledging that different people have different life experiences because of their race, ethnic background, national origin or sex, and that race is a social construct with no genetic basis (Race & Genetics Working, 2005). In order to have a common language for discussion of topics that are new to some participants, we provide the following terms with definitions.

3.1 | Explicit bias

Explicit bias consists of consciously endorsed attitudes, behaviors and actions that are prejudiced in favor of one individual or group compared to another. Examples of institutionalized bias include slavery, the caste system, and apartheid (Wilkerson, 2020).

3.2 | Implicit or unconscious bias

Implicit bias refers to pervasive, subconscious attitudes or cultural stereotypes about other people based on their appearance (including race, ethnicity, sex, or age) that affect understanding, actions and decisions in an unconscious way (Greenwald & Banaji, 1995).

3.3 | Microaggression

Microaggressions are defined as brief and common daily verbal, behavioral, and environmental communications, whether intentional or unintentional, that transmit hostile, derogatory, or negative messages to a target person because he or she belongs to a stigmatized group (Sue et al., 2007).

4 | BACKGROUND

Discrimination based on race, color, or national origin in admission policies to graduate school or medical school, was outlawed by Title VI of the Civil Rights Act of 1964. Title IX of the Education Amendments of 1972 prohibits discrimination in education programs based on sex. Therefore, systematically and explicitly excluding people from educational opportunities based on ethnicity and sex has been greatly

 © 2020 Wiley Periodicals LLC

reduced over the past 50 years; in contrast, implicit bias continues at every stage of professional development. A recent study of minority resident physicians (those of Black, Hispanic/Latin, Native American or mixed ancestry) found they still suffer a daily barrage of microaggressions and bias (Osseo-Asare et al., 2018). Furthermore, implicit bias may affect clinical decision making (Chapman et al, 2013).

We have found that it is helpful for the moderator to begin by sharing a personal story of experiencing microaggression or explicit or implicit bias during his or her own career. Alternatively, a published vignette can be shared, asking the audience to put themselves in the shoes of the author. Dr Roberto Montenegro wrote a personal essay about the painful experience that occurred one evening when he and his wife were invited by his faculty mentor to celebrate completion of his doctoral dissertation (Montenegro, 2016). After enjoying an elegant dinner, while waiting for the valet to bring their car, he was mistaken not once, but twice by well-dressed customers who assumed, based on his appearance, that he was a valet. At that moment, he describes his feelings of being dismissed, invisible, helpless, and wondering if he would ever be good enough.

We have also used articles which provide case studies of microaggressions in the academic and clinical setting which allow the participants to explore how they would respond to incidents in which they are either the target or a bystander (Wheeler, Zapata, Davis, & Chou, 2019), or a study which found both male and female science faculty demonstrating gender bias favoring male students when presented with identical curriculum vitae using either male or female applicant names (Moss-Racusin, Dovidio, Brescoll, Graham, & Handelsman, 2012).

5 | SMALL GROUP EXERCISE

After the introductory presentation to the entire group, we recommend breaking up into small groups consisting of 6–10 people in order to have meaningful discussions about diversity.

We recommend assigning a leader for each small group, who asks each person to introduce herself or himself. We have used the following ground rules for the small group discussions:

1. The discussion can focus on one of the articles provided or on personal stories from members of the small group.
2. Anyone can volunteer to speak about his or her own experience, but no one should be forced to share an experience.
3. Listen respectfully; do not interrupt or minimize someone else's story.
4. Keep an open mind.

Fabiola Quintero-Rivera MD. At one ACMG meeting, our table consisted of eight participants randomly assembled and passionate for medical genetics: one ABMGG laboratory genetics fellow, one PhD student, one medical student, four Genetic counseling students, and two faculty. We asked people to self-reported ethnicity and gender identification if they were comfortable. Our table had two Asians, two Whites, two Latin-Americans, one person from the Middle East, and one African-American, as well as one individual identifying as LGBTQA+. There were seven females and one male. Ages ranged from 20's to 60's, although most were in their 20's. Four participants were born and raised in the United States.

The small group discussion at the table was particularly meaningful. Our group leader, an African-American graduate student, set the stage through her willingness to share her own stories. She talked about growing up and being told that she was different and not like other black people. She received comments such as "*you are so articulate*" and "*you don't act African-American*." She also spoke about how she feels having to live in two worlds: the African-American culture, and the White culture of academia. Members of our table then shared stories about how their race and ethnicity had affected their personal lives more than their academic lives, but they all carried those burdens with them into academia.

A student shared what it was like being the only Asian person in an all-white school, and the resentment she felt for being stereotyped, even in supposedly positive ways. She commonly heard things like "*you must be really good in math*," or was asked "*what musical instrument do you play*?" The other Asian student shared her interactions with "*a professor who after several interaction in a small group setting, could seem to remember every name but mine*."

The LBGTQ+ trainee shared a situation where a passerby yelled at her that she "*would go to hell*" while holding hands with her wife as she walked down the street.

Another microaggression cited by multiple participants was being asked "*where are you from?*"

Other stories included a mother being mistaken as the nanny of her mixed-race child, and a participant being told by a male colleague that "*too many women trainees have been recruited lately in the department; we should start recruiting men again*."

Fuki M. Hisama MD. At an ASHG meeting, during small group discussions, an African trainee shared that he was *assumed to be less competent, until he had proven himself to be qualified*. A trainee from South America said that when he met Americans in the community, after always being asked where he was from, he was asked when he was planning on returning home. The listeners recognized that this question, although superficially neutral, contained an underlying, perhaps unconscious message that he was not welcome in the United States. A white faculty member responded to the commentary by Roberto Montenegro by recognizing that he *had never in his life experienced been mistaken for being a valet, or a janitor, and that he had not considered this perspective before*. At the 2019 ASHG meeting, one trainee came up to me and said "*The Diversity Breakfast has changed my life!*"

6 | CONCLUSIONS

This forum at national genetics meetings has allowed participants to share these personal, and painful stories. We have not systematically collected responses from all participants, but over several years, we have heard from participants from underrepresented groups who have

shared similar feelings, and agreed that at times their ethnic background (or sex or sexual orientation) spoke louder about who they were than their character did. Furthermore, they recognized that there is often a discrepancy between a well-meaning speaker's *intent* and the *impact* on an minority individual. A speaker from a majority background may ask what feels like an innocent question expressing interest, but to the minority recipient, the question or statement is received with a subtext of "*you are different, and you don't belong here*."

A white female trainee shared with the group that "*it was an eye-opening experience for me to hear the stories shared. I grew up in a homogeneous community where everyone looked like me, and I have always taken for granted all the privileges I have access to*." Finally, another participant in a small group discussion wrote afterward that "*I was so struck and moved by the individual stories that I was without words, literally, speechless. It was one of the most productive hours I have spent at this year's College meeting*."

FUTURE DIRECTIONS

No single demonstration, march, editorial, speech, or workshop can result in lasting change. It can, however, signal the will to change, and the beginning of a new era. To truly effect a lasting change will take unflagging, consistent dedication, and hard work. A good start will be truly listening to our peers from underrepresented groups, and having an ongoing open dialogue with the leaders in healthcare, science, and academia to impress on them that diversity, inclusion, and equity are not "extras" that are nice to have, but are central to our missions of improving health through genetics, research to enable discovery, and educating the next generation and members of the public. The time to act is now.

ACKNOWLEDGMENTS

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any other agency, organization, employer or company. Neither Dr Quintero-Rivera nor Dr Hisama has any conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

n/a.

Fabiola Quintero-Rivera[1]
Fuki M. Hisama[2]

[1]*Department of Pathology and Laboratory Medicine, University of California Irvine School of Medicine, Irvine, California*

[2]*Department of Medicine (Medical Genetics), University of Washington School of Medicine, Seattle, Washington*

Correspondence
Fuki M. Hisama, Department of Medicine (Medical Genetics), University of Washington School of Medicine, Seattle, WA, USA.
Email: fmh2@uw.edu

ORCID

Fuki M. Hisama https://orcid.org/0000-0001-7772-7855

REFERENCES

Chapman, E.N., Kaatz, A., & Carnes, M. (2013). Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities. *Journal of General Internal Medicine*, *28*(11), 1504–1510. https://doi.org/10.1007/s11606-013-2441-1

Greenwald, A. G., & Banaji, M. R. (1995). Implicit social cognition: Attitudes, self-esteem, and stereotypes. *Psychological Review*, *102*(1), 4–27. https://doi.org/10.1037/0033-295x.102.1.4

Montenegro, R. E. (2016). A piece of my mind. My name is not "interpreter". *Journal of the American Medical Association*, *315*(19), 2071–2072. https://doi.org/10.1001/jama.2016.1249

Moss-Racusin, C. A., Dovidio, J. F., Brescoll, V. L., Graham, M. J., & Handelsman, J. (2012). Science faculty's subtle gender biases favor male students. *Proceedings of the National Academy of Sciences of the United States of America*, *109*(41), 16474–16479. https://doi.org/10.1073/pnas.1211286109

Osseo-Asare, A., Balasuriya, L., Huot, S. J., Keene, D., Berg, D., Nunez-Smith, M., … Boatright, D. (2018). Minority resident physicians' views on the role of race/ethnicity in their training experiences in the workplace. *JAMA Network Open*, *1*(5), e182723. https://doi.org/10.1001/jamanetworkopen.2018.2723

Race, E., & Genetics Working, G. (2005). The use of racial, ethnic, and ancestral categories in human genetics research. *American Journal of Human Genetics*, *77*(4), 519–532. https://doi.org/10.1086/491747

Sue, D. W., Capodilupo, C. M., Torino, G. C., Bucceri, J. M., Holder, A. M., Nadal, K. L., & Esquilin, M. (2007). Racial microaggressions in everyday life: Implications for clinical practice. *The American Psychologist*, *62*(4), 271–286. https://doi.org/10.1037/0003-066X.62.4.271

US Centers for Disease Control and Prevention. (2020). *Demographic trends of COVID-19 cases and deaths in the US reported to the CDC*. Retrieved from https://www.cdc.gov/covid-data-tracker/index.html/#demographics.

Webb Hooper, M., Nápoles, A. M., & Pérez-Stable, E. J. (2020). COVID-19 and Racial/Ethnic Disparities. *JAMA*, *323*(24), 2466. https://doi.org/10.1001/jama.2020.8598

Wheeler, D. J., Zapata, J., Davis, D., & Chou, C. (2019). Twelve tips for responding to microaggressions and overt discrimination: When the patient offends the learner. *Medical Teacher*, *41*(10), 1112–1117. https://doi.org/10.1080/0142159X.2018.1506097

Wilkerson, I. (2020). *Caste: The origins of our discontents* (1st ed.). New York: Random House.