

An Update for the National Advisory Council for Human Genome Research The American Society of Human Genetics, Mona Miller, Executive Director February 2018

ASHG Annual Meeting Update: ASHG hosted a successful 2017 Annual Meeting with excellent science, strong attendance, and positive feedback from the community. ASHG was particularly honored to host a special Presidential Symposium with Bill Gates of the Bill and Melinda Gates Foundation and Dr. Francis Collins, which was an extraordinary opportunity for the community – the event is available online <u>here</u>. The 2018 Annual Meeting will be held in San Diego Oct. 16-20; the abstract deadline is June 7. The *Preliminary Program Schedule* is available here, subject to change by the Program Committee. Joint collaborations will be held with the Pharmacogenomics Research Network, the International Society for Computational Biology, and the International Genetic Epidemiology Society.

The American Journal of Human Genetics: In December, ASHG thanked outgoing Editor-in-Chief David Nelson, PhD (now ASHG President) for his service. Dr. Nelson wrote a final <u>editorial</u> reflecting on his tenure, exciting future field directions, and his particular interest in recognizing and memorializing the history of the field. In January, the Society and *The Journal* welcomed as new Editor-in-Chief Bruce Korf, MD, who published his first <u>editorial</u> outlining his interests. AJHG also reflected on the passing of Arno Motulsky, past ASHG president and *AJHG* editor in chief. *AJHG* and <u>ASHG</u> posted obituaries and sent a note of appreciation to the Motulsky family.

Field Recognition Awards and Governance Service Opportunities: ASHG will open its 2018 <u>Awards</u> site in early March. Nominations for 2019 <u>ASHG Board of Directors</u> and <u>committee</u> positions will also open in March. The Board always encourages and seeks more field nominations from which to select award winners and Society leadership. It also encourages nominations that help ensure award winners and volunteers increasingly reflect the scientific, demographic, career stage, and international diversity of the ASHG membership.

Media and Communications: ASHG continues to provide scientific background and comment to a wide variety of news outlets. ASHG Past President <u>Nancy Cox published an opinion-editorial in the Orlando Sentinel</u> on the importance of genetic diversity, which expanded on her thoughts from her Annual Meeting <u>Presidential Address</u>. ASHG is also increasing communication within the human genetics community to inform and engage members and the field. Recent ASHG blog posts include: <u>Policy and Advocacy: 2017 Highlights; How to Craft a Competitive Invited Session; The ASHG's Social Issues Committee Initiation of a New Duty to Recontact Statement; NIH Redefines Clinical Trials and Sets New Requirements: Is Your Human Subjects Research Affected?; What You Need to Know About FDA Oversight of Genomics Research; Expanding Role for Genetic Counselors: Good for Our Profession, Great for Our Patients.</u>

"Public-Facing Education" – K-12, Outreach & Engagement, Undergrads: The 13th annual ASHG DNA Day Essay Contest launched in January and the winner will be announced on DNA Day. We're getting inquiries and interest from many students and teachers, as well as an energized volunteer corps of ASHG members who review the essays – last year, 500 members reviewed thousands of submissions from 38 U.S. states and 21 countries. This year's question is: *Do you think medical professionals should be required for all genetic testing, or should consumers have direct access to predictive genetic testing?* The ASHG team is also increasingly engaged with GLEE, the NHGRI team, and the larger NHGRI community to promote the *Fifteen for Fifteen* Campaign and will be spreading the word and urging ASHG members to become (and stay) involved in public outreach. The Undergraduate Workshop will be held again this year before the ASHG Annual Meeting. ASHG members are piloting a new approach to the High School Workshop, going directly into San Diego classrooms.

"Field-Facing" Education – Career and Professional Development, Trainees, and Diversity: ASHG will continue a popular line-up of career and professional development sessions during the Annual Meeting, and the Society is exploring new topics on mentoring and for early-career scientists. ASHG will again host an ASHG-sponsored Diversity Breakfast, supporting efforts by long-time ASHG members committed to diversity. In

2017, ASHG participated in the Federation of American Societies for Experimental Biology (FASEB) grant program to fund annual meeting attendance and mentoring experiences for emerging scientists from URM communities. Thirteen trainees were sponsored last year and ASHG will participate again this year. ASHG will also participate in upcoming FASEB discussions about possible new diversity initiatives.

Health Professionals Education: Following discussion and a vote at the fall Board of Directors meeting, ASHG will sunset its non-genetics health professionals education program, continuing existing programming through October 2018. Appreciating the hard work, partnerships, and accomplishments of the project and its value as an important ASHG program experiment, the Board also sees many additional needs or opportunities in the education arena where the Society may be better positioned to have a substantial impact on the public and ASHG's core constituencies, and it will be exploring those opportunities. In 2018, ASHG will complete several activities. Staff collaborated to produce and submit to ACMG a poster on ASHG's cfDNA project; it was accepted and ASHG will present it along with Mayo Clinic and Kaiser partners. Staff will produce new resources for the speech and hearing community through an ongoing American Speech-Language-Hearing Association (ASHA) partnership; finish an oncology initiative started in 2017; and complete other final projects.

Partnerships in the community: ASHG staff is working with NSGC staff on content for an event for the 2018 NSGC meeting and will continue dialogue about shared opportunities. Leadership of ASHG and ACMG will meet in Charlotte to discuss areas for possible collaboration or coordination.

Policy Analysis and Action: Following Board approval, the Social Issues Committee is developing an ASHG 'Duty to Recontact' statement to provide guidance to the genetics research community. ASHG also submitted <u>comments</u> to the National Academies Committee on the Return of Individual-Specific Results Generated in Research Laboratories and submitted <u>comments</u> to the FDA regarding their proposed framework for regulating DTC genetic health risk tests. ASHG will host a second Policy Luncheon at the Annual Meeting.

Advocacy: Through its new Advocacy Center, ASHG launched a campaign regarding tuition waivers taxation, asking U.S. members to contact Congress expressing opposition to changes being considered as part of tax reform, and partnered with the other FASEB societies in issuing a statement to Congress. ASHG is increasing its engagement with FASEB, the Ad Hoc Group for Medical Research, Research!America and others to strongly support NIH funding, and signed on to a letter to congressional leadership in support of raising federal spending caps and appropriating \$36.1 billion for NIH in FY 2018. It will engage more actively in the coming weeks as Congress finalizes federal spending for FY 2018. Also, ASHG is increasingly engaged with the larger advocacy community and meeting regularly with FASEB, Research!America, AAAS and other society leaders to coordinate support for biomedical research and the scientific enterprise more broadly. A first annual Advocacy Event is being piloted at the Annual Meeting to encourage greater ASHG member advocacy engagement.

ASHG/NHGRI Fellowships: The 2016/2017 Genetics and Education Fellow Teresa Ramirez completed her fellowship and accepted a position as a FASEB program manager focusing on diversity and inclusion in science. The 2016-2017 Genetics and Public Policy Fellow Christa Wagner has also completed her fellowship and has joined the Association of American Medical Colleges as a legislative analyst. 2017-2018 Genetics and Public Policy Fellow Nikki Meadows has completed her rotation of the fellowship at NHGRI; she began her Capitol Hill rotation in January in the office of Rep. Louise Slaughter (D-NY). The 2018 selection process is underway.

Organizational: ASHG welcomes Kelly Ventura as its new Senior Director for Education and Membership. Kelly joins the Society from the American College of Cardiology where she led a team to develop and expand efforts that engage ACC members in the life of their society and partner with education teams to build and promote these programs to serve multiple audiences. She will be working with ASHG Executive Director Mona Miller, the ASHG Board, and other senior staff on strategic planning for both membership and education initiatives, as well as supporting ASHG staff in important on-going education programs activity. In mid-2018, ASHG will move its headquarters to 6120 Executive Boulevard in Rockville, MD. Staff preparations and office construction are underway. ASHG is also prioritizing substantial investment in new administrative, technology, and data infrastructure strategies to support future programming in all areas.