International Summit in Human Genetics and Genomics, 2019

The International Summit in Human Genetics and Genomics was hosted by NHGRI on the NIH campus, from August 28th –September 28th, 2019. It was the fourth of the 5- year (2016-2020) trans-NIH initiative to advance genetics and genomics in research and medicine, in low to middle income countries (LMIC; World Bank). Based on last year's success, two additional ICs (NCATS, NIA) participated this year, for a total of 15 ICs, including FIC, NCI, NEI, NHGRI, NHLBI, NIAID, NICHD, NIDA, NIDCD, NIDCR, NIMHD, NINDS and NINR.

As mortalities from more common diseases and disorders decline, genetic disorders and congenital birth defects consume a disproportionate level of resources allotted to health care. Many LMICs lack expertise in genetics and genomics. This impacts the required training for the provision of care and contributes negatively to the welfare of these nations. The International Summit aims to alleviate these issues by filling the knowledge gap in human genetics and genomics.

With generous support from ICs at NIH and donations made to the Foundation for the NIH (FINH) by ACMG, ASGCT, ASHG, Mayo Clinic, Sanford Health and Sarepta Therapeutics, 34 candidates from 24 countries (refer to world map on reverse side) attended the Summit. Participants included research scientists (6), physicians (17) physician/scientists (3), physician/PhD(c) (2), physician/counselor (1), dentist/scientists (2), nurse/scientist (1), counselor (1) and clinical psychologist (1).

The curriculum included 11.5 days of didactics in genetics/genomic research and medical genetics; 5 days of mentoring in the participants' area/s of interest; 3 days of field trips. Over 70 speakers delivered 70+ lectures (ISHGG 2019_Agenda), including on new topics (genomics of malaria, TB, mental illness, substance use, etc.). The training included hands-on workshops in bioinformatics, grant writing, genetics clinic and patients The field trips included visits and lectures at academic and commercial institutions, that provide clinical and laboratory services (Children's National Health System, GeneDx, Johns Hopkins University, Kennedy Krieger Institute, Maryland Public Health Laboratories, MedStar Washington Hospital Center, National Center for Advancing Translational Sciences, NIH Clinical Center, NIH Intramural Sequencing Center). These visits informed the participants of the spectrum of experts, infrastructure and systems involved in the provision of genetic services and testing. Approximately one third of participants identified the week of personalized training as their favorite part of the Summit. Grant writing, bioinformatics workshop and the patient panel were additional favorites of the Summit. Several patients shared their insights, struggles and continuing needs, because of the genetic diseases affecting them or their family members. Participants described the Summit as "visionary", "life changing", "amazing" "career enhancing" and "an opportunity to interact literally with the world."

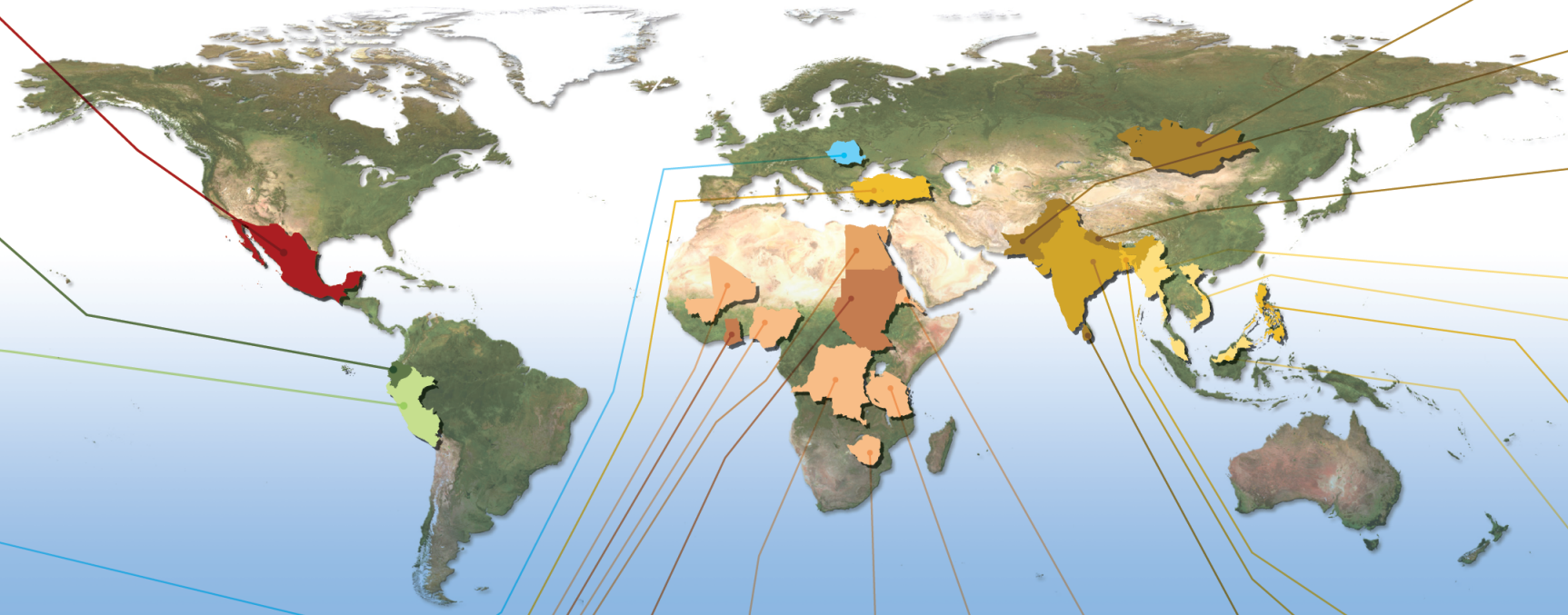
To measure outcomes, we assessed prior knowledge, learning and interest through daily pre- and post-curriculum surveys. The results were consistent with those of previous years which describe the Summit as a unique learning opportunity for participants and speakers, and they strongly encouraged its continuance. All activities were rated as imparting knowledge and important to include in next year's summit.

The 2018 annual outcome (2016/17/18 batches) has been remarkable (ISHGG 2018_Annual Outcome). Participants established collaborations (64) with investigators at NIH, other US-based academic institutions and amongst themselves; Published articles (177, in various stages), in their field of expertise and related to genetics; Wrote/received grants to/from NIH or other funding agencies (53); Initiated new research and/or clinical projects (38) and influenced the course of ongoing research projects (49). Our assessment of outcomes will continue for 5-years with every cohort.

Based on the survey feedback (2019) and 2018 outcomes, the Summit has made good progress in achieving its goals and is in popular demand. Thus, in 2020, we hope to host up to 40 candidates. This however will only be possible with support from our Institutes and Centers at NIH and the FNIH.

Fourth International Summit in Human Genetics and Genomics

National Institutes of Health, Bethesda, Maryland, August 28 - September 28, 2019



Mexico

Jorge Eduardo Ortiz Panozo

Bethania López

Ecuador

Arianne LLamos Paneque

Peru

Solange R. Paredes Moscosso

Romania

Radu Pîrlog

Turkey

Yeliz Guven

Meltem Ece Kars

İlknur Yeşilçinar

Mongolia

Naranchimeg Baatar

Pakistan

Muhammad Iqbal

Nepal

Pratiksha Gyawali

Myanmar

Aye Kyawt Khant

Vietnam

Luong Hoang Long

Philippines

Ma-Am Joy R. Tumulak

Malaysia

Norita Hussein

Shing Yiing Tiong

Mali

Abdoulaye Bocoum

Ghana

Samuel Agyei Wiafe

Nigeria

Henrietta Ifechukwude Monye

Olukayode O. Akinmola

Lukman Adewale Alli

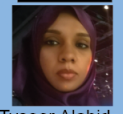
Sanusi Abubakar

Oluyomi Okunola

Egypt

Inas Sayed

Sudan


Tyseer Alabid Elsiddig Hag Alamin

Democratic Republic of Congo

Kizito Mosema Be Amoti

Zimbabwe

Kudakwashe Mhandire

Tanzania

Theophylly L. Mushi

Eritrea

Yishak Gebrekidan Weldemichael

Sri Lanka

Givani Amarakoon

India

Deepti Mutreja

Lekshmi S Nair

Sakshi Yadav

Bangladesh

Enamul Hoque Chowdhury