

2018 International Summit in Human Genetics and Genomics

August 29, 2018 – September 29, 2018

BACKGROUND

The Foundation for the National Institutes of Health (FNIH) invites your organization to sponsor the second annual International Summit in Human Genetics and Genomics. **The National Human Genome Research Institute (NHGRI) developed the four-week Summit to assist healthcare professionals from countries with limited resources who cannot otherwise afford to receive advanced training in genetics and genomics research.**

The Summit will sponsor up to 30 early- and mid-career Ph.D.s, M.D.s, dentists, nurses, counselors and graduate/medical school trainees to obtain in-depth training from the field's foremost experts in genetics and genomics at the National Institutes of Health (NIH) in Bethesda, Maryland. **The Summit addresses two of the United Nation's Sustainable Development Goals: #3 Good Health and Well Being; and #9 Industry, Innovation and Infrastructure.**

PROGRAM DESIGN

The International Summit in Human Genetics and Genomics is a five-year training initiative, which began in 2016 and will conclude in 2020. Leveraging the success of its first two years, NHGRI is launching the third year of the Summit, with the ultimate goal of better integrating genetics and genomics in low-to-middle income countries.

The Summit is designed to advance the following objectives in developing nations:

- Increase the working knowledge of genetics and genomics among researchers and healthcare professionals
- Reduce the lag time for incorporating genetics and genomics in research and clinical practice
- Integrate relevant technologies in clinical practice to facilitate diagnosis, treatment and disease management
- Encourage newborn screening for early detection of genetic disorders
- Facilitate personalized/precision medicine for targeted disease treatment
- Educate healthcare workers and scientists on the ethical, legal and social implications (ELSI) of genetic information
- Help to build nationwide capacity in genomic research and medicine
- Improve access to delivery and management of safe genetic services
- Equip researchers and professionals to advocate for genetics and genomics
- Reduce health disparities and the burden of disease and disability on individuals and economies

The 2017 Summit brought together 26 trainees from 24 countries including: 12 physicians; five scientists; three dental researchers; three research scientists; two Ph.D. candidates; and one nurse.

Outcomes from the 2017 Summit have been remarkable. Following the Summit, participants have established collaborations with their fellow trainees, investigators at NIH and researchers at U.S. academic institutions. **51 have published genomic-focused articles in their field of expertise and 24 have submitted grant applications to NIH or other funding institutions.** As part of their acceptance into the program participants have agreed to provide ongoing feedback and complete outcome assessments over the next five years.

PROVEN TRAINING MODEL

Dr. Vorasuk Shotelersuk's experience exemplifies the impact this training program can have. A researcher and pediatrician from Thailand, Dr. Shotelersuk trained with the Medical Genetics Branch at NHGRI. Upon returning to Thailand, he shared information and training that led to establishing medical services and research opportunities in Tropical Genetic Diseases in Thailand.

Now Head of the Division of Medical Genetics and Metabolism in the Department of Pediatrics at King Chulalongkorn Memorial Hospital in Bangkok, Dr. Shotelersuk published a book entitled *Clinical Genetics in Children*, which is the equivalent of Smith's *Recognizable Patterns of Human Malformations for Thai Ethnicity*.

Today, Thailand has 22 clinical geneticists and has offered training fellowships since 2014. With the help of the Red Cross, the country has invested in outreach clinics to treat children with oral clefts and has expanded research opportunities in rare and common genetic diseases and infectious diseases.

In 2017, participants visited academic and commercial institutions that provide clinical and laboratory services including: Children's National Health System, GeneDx, Johns Hopkins University, NIH Intramural Sequencing Center, Kennedy Krieger Institute, and MedStar Washington Hospital Center. These trips familiarized the participants with the spectrum of organizations involved in genetic services and testing. This year the Summit participants will continue visits to various research facilities in the D.C. Metro Area.

The 2018 curriculum will mirror that of the previous year, which included three weeks of didactics in genomic research and clinical genetics medicine, and one week of advanced training in the participants' areas of interest. The training also included a bioinformatics workshop with hands-on data analysis, exposure to genetics clinics and weekly fieldtrips. **The 2017 Summit featured more than 50 speakers who presented approximately 60 lectures on a variety of topics.**

TRAINING & CAPACITY BUILDING

Though the Summit only has the capacity to train 30 individuals a year, it will have exponential impact as trainees return to their countries of origin and share their knowledge. Most existing training efforts in under-resourced countries begin at the grassroots level with non-governmental organizations and local governments, and later expand to state and national levels. To encourage this type of dissemination, NHGRI selects Summit participants from low-resource countries with infrastructure that collaborate with academic institutions and with international agencies like: UNESCO; UNICEF; World Health Organization; and the National Newborn Screening & Genetics Resource Center. When Summit participants return to their countries, they will be in the position to maximize their training by building on this infrastructure.

Technology is pivotal in enabling participants to disseminate their training. In countries with limited research and medical facilities, telemedicine plays an important role. Participants will be encouraged to set up and participate in on-line networking platforms to facilitate an exchange of ideas and present opportunities for research, collaborations and case-discussions at the local, regional and national levels. Through using this technology, Summit participants and their peers will be able to collaborate virtually.

To facilitate Summit participants' efforts to integrate genetics and genomics into their national healthcare systems, NHGRI will invite Scientific Counselors from their Embassies to attend specific sessions. These sessions will cover the importance of genetics and genomics, as well as various models of delivery.

SPONSORSHIP AND PARTNER INVOLVEMENT

The FNIH invites your organization's investment of \$10,000 to help support the 2018 International Summit in Genetics and Genomics. This sponsorship is pivotal to the program's success, as it provides essential funds to offset the costs of the trainees' housing, meals, incidentals and field trips. **Your investment enables you to participate in the Summit by helping to identify training candidates and providing curriculum and technology support. Investment partners will also be invited to attend and have a role in select sessions.**

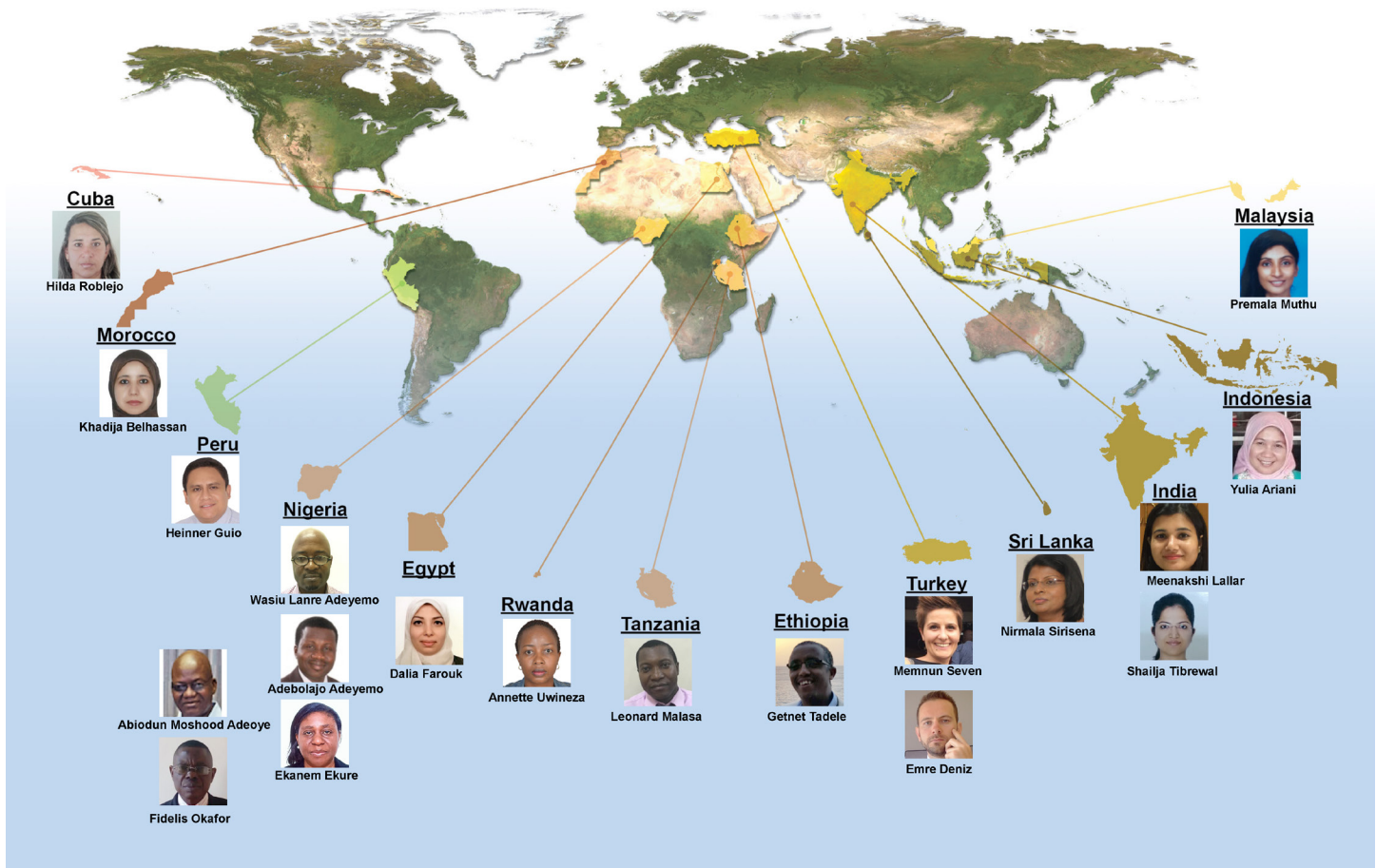
To learn more about the Summit please visit our website at: fnih.org/internationalsummit.

For more information about sponsoring, please contact:

Shawn Stern
Development Associate
Foundation for the National Institutes of Health
11400 Rockville Pike, Suite 600
Bethesda, MD 20852
301-827-5824
sstern@fnih.org

First International Summit in Human Genetics and Genomics

National Institutes of Health, Bethesda, Maryland, September 1 - 30, 2016



ABOUT THE FNIH

The Foundation for the National Institutes of Health (FNIH) creates and manages alliances with public and private institutions in support of the mission of the NIH, the world's premier medical research agency. The Foundation, also known as the FNIH, works with its partners to accelerate biomedical research and strategies against diseases and health concerns in the United States and across the globe. The FNIH organizes and administers research projects; supports education and training of new researchers; organizes educational events and symposia; and administers a series of funds supporting a wide range of health issues. Established by Congress in 1996, the FNIH is a not-for-profit 501(c)(3) charitable organization. For additional information about the FNIH, please visit www.fnih.org.

ABOUT NHGRI

The NHGRI began as the National Center for Human Genome Research (NCHGR) in 1989 to carry out the role of the NIH in the International Human Genome Project (HGP). The HGP was developed in collaboration with the United States Department of Energy and began in 1990 to map the human genome. In 1993, NCHGR expanded its role on the NIH campus by establishing the Division of Intramural Research to apply genome technologies to the study of specific diseases. In 1996, the Center for Inherited Disease Research (CIDR) was co-funded by eight NIH institutes and centers to study the genetic components of complex disorders. In 1997, the United States Department of Health and Human Services renamed NCHGR the NHGRI, officially elevating it to the status of research institute—one of 27 institutes and centers that make up the NIH.