

38. **Tibrewal S**, Ratna R. Perceptions of Ophthalmologists regarding the need to genetic counseling in India, for hereditary eye diseases. (Submitted to IRB).

**E. Ongoing Research Projects:** (Total- 49; 2018- 9; 2017- 18; 2016- 22)

2018 Batch

1. **Cornejo-Olivas M**, Smichdt T, Gordon C, Franca M. The EUSAge study: European-South American collaborative Project to identify and characterize age related genetic modifiers and biomarkers of neurodegenerative processes in SCA3/MJD. (Summit lectures in neurogenetics improved study execution).
2. Jaja C, **Edem-Hotah J**, Mustapha I, Bell N, Barrie N, et al. Incidence and Prevalence of Sickle Cell Disease (SCD) in Sierra Leone. (Summit reinforced idea of a registry for recording and tracking SCD population).
3. Kosiyo P, Otieno W, **Gitaka J**, Nyamuni J, Ouma C. Sickle cell genotypes in malaria. (Molecular techniques learnt during the Summit improved protocol development).
4. Margaret Pericak-Vance, **Cornejo-Olivas**. Genetics of dementia in a Peruvian cohort. (Summit lectures in Bioethics in genetic research and Scientific article writing improved informed consent form and writing of manuscript).
5. **Mburu S**. Tumor Microenvironment Heterogeneity and Individual Variabilities: Promising Precision Medicine Targets in Myeloid Neoplasms and Acute Leukemias; A Systematic Review (Meta-synthesis). (Summit helped strengthen concept of Precision medicine-response to treatment, prognosis, evolution of malignancies, targeted therapies in myeloid neoplasms and acute leukemias).
6. **Messaoud O**, Romdhane L, Naouali C, Belhaj O, et al. Genetic characterization of atypical forms of photogenosermatosis. (Knowledge gained from personalized trainings at Summit helped with interpretation of incidental findings, exome data analysis).
7. **Messaoud O**, Chimusa E.R, Ahmed A, Mainzer L, et al. Integrative Multi-omics-based Simulation Framework project. (Summit increased awareness; encouraged to be part of other consortia).
8. **Mistri M**, Sheth J. Multicentric collaborative study of lysosomal storage disorders (LSDs) in India. (Knowledge gained at Summit improved research quality).
9. **Nakousi-Capurro N**, Huserman J, Castillo S, Herrera L, et al. Knobloch Syndrome in a patient from Chile. 2019. (Observation of research and team work at NIH during the Summit, raised research standards).

2017 Batch

10. **Avogbe PH**, Le Calvez-Kelm F, et al. Whole transcriptional profiling and gene expression analysis in urothelial carcinoma. (Data analysis started).
11. **Benítez Cordero Y**. Characterization and development of an integrated system for management of major congenital defects in Cuba for the period 2007-2020. (Summit helped reaffirm usefulness of data registries for genetic epidemiological studies).
12. **Casado PL**. Analysis of 7 different techniques to isolate microRNA. (Summit Bioinformatics lecture provided clarity on relationship between miRNA, DNA and mRNA; improved execution of project).

13. **Casado PL.** Genetic profile of patients that underwent peri-implant maintenance therapy: relationship with peri-implant disease incidence. (Knowledge from Summit helped improve sample collection, medical history analysis, selection of the main related genes in multifactorial peri-implant diseases).
14. **Dhoro M,** Mujuru H, Kaisi D and Dingswayo P. Determine the status of congenital disorders at Parirenyatwa Hospital, Harare, Zimbabwe. (Summit helped develop proposal to fill data gap on prevalence and characterization of genetic disorders in sub-Saharan Africa).
15. Hammad SA, **Otaify GA,** **Ahmed DF,** Assem E, Aglan M, et al. Predictive Cytogenetic Biomarkers for non-disjunction disorders. (Knowledge gained from Summit improved reporting of results).
16. Kholoussi N, **Otaify GA,** Helwa E, Aglan MS, et al. Immunogenetic approach in diagnosis and prognosis of some genetic disorders. (Knowledge gained from Summit improved reporting of results).
17. Marcheco Teruel B, **Benítez Cordero Y,** Suárez Besil B, et al. Evaluation of the impact of the National Program for diagnosis, handling and prevention of genetic diseases and congenital defects. (Summit helped reaffirm usefulness of data from different specialties for-development of personalized medicine, clinical validity of gene-disease associations, registries for genetic epidemiological studies).
18. **Otaify GA,** Aglan MS, AbdelHamid MS, Mehrez MI, et al. Clinical and molecular study of patients with inherited metabolic bone disorders. (Knowledge gained from Summit improved reporting of results).
19. Rinaldi S, **Torres-Mejía G,** Sánchez G, Garmendia Ma L. Molecular Subtypes of Premenopausal Breast Cancer in Latin American Women (PRECAMA): a multicenter population-based case-control study (IARC 2012- Continued).
20. **Roy S.** Effect of Early Treatment with Oral Propranolol on Periocular Capillary Haemangioma on Outpatient Basis. (Continued).
21. Sewankambo N, **Wayengera M.** Prevalence of polymorphic genes of Alzheimer's disease in nodding disease tauopathy. (NURTURE Supplementary fellowship).
22. Suarez Besil B, **Benítez Cordero Y,** et al. Community strategy for the promotion-prevention of genetic health in primary health care. (Continued).
23. Temtamy S, **Otaify GA,** Kholoussi N, Aglan M, Zaki MS. Recent advances in the diagnosis, management and research of genetic diseases. (Knowledge gained from Summit improved reporting of results).
24. **Tuncay FY,** Dinçer P. Evaluation of phenotypic effects of genome editing mediated TGFBI variation on zebrafish cornea. (Summit contacts helped resolve issues with project).
25. **Tuncay FY,** Ünlü M. Genetic analysis of a family with anterior segment dysgenesis. (Summit helped plan, explain importance of participation in project to patients, families, clinicians).
26. Vaca F, **Torres-Mejía G,** Díaz Velázquez CE, Martínez Razo G, Moreno Macías H. Identification of pathogenic variants of susceptibility to early-onset breast cancer in young women (Continued).
27. **Yousef YA,** Mehayar M, Mosallam M. The impact of RB1 type gene mutation in clinical presentation and management of outcome, in retinoblastoma patients. (Summit helped understand need and impact of types of mutations, presentation, response to management).

2016 Batch

28. **Adeoye AM**, Ayede AI. CARdiovascular rIsk Factors and diseases among pregnant women and their Foetal outcome in Ibadan (CARDIFF Study). (Continued).
29. **Adeoye AM**, Kuti M. Carotid intima media thickness and lipid markers of atherosclerosis among hypertensives. (Continued).
30. **Adeoye AM**, Owolabi MO. Exploring the phenomics, genomics and environmental determinants of left ventricular mass among offspring of hypertensive African Blacks: A family screening study. (Continued).
31. **Adeoye AM**, Raji RY. The role of Renin Angiotensin Aldosterone pathway genetic polymorphisms in circadian blood pressure variations in Nigerian patients with chronic KIDney disease (RAASKID Study). (Continued).
32. **Deniz E**. Genome-wide screening with CRISPR/Cas9 and modelling of resistance mechanisms developed against cytotoxic drugs in cancer treatment. (Knowledge from Summit in personalized medicine and genomic information helped write proposal, analyze bioinformatics data).
33. **Ekure EN**, Bode-Thomas F, Sadoh WE, Orogade AA. Nigerian pediatric cardiac disease registry. (Summit reinforced relevance of registry for congenital heart disease).
34. Gakuru Angelique, **Uwineza A**. Patterns and risk factors for congenital abnormalities in tertiary health facilities in Rwanda. (Summit identified the need to implement a birth defect registry in Rwanda).
35. Helmy N, **Hussen DF**. Using of microarray technique in diagnosis of agenesis of corpus callosum. (Continued).
36. Mahmoud A, **Hussen DF**. Nicotine dependence as an environmental health problem, the efficacy of different approaches for its management. 3-year project. (Continued).
37. Nkya S, Mtei L, **Malasa L**, Soka D, Mdai V, Mwakale P, et al. Newborn screening for sickle cell disease in Dar es Salaam, Tanzania. (Knowledge gained from Summit supported implementation).
38. Olatosi O, **Adeyemo WL**, Butali A. Investigating the genetic causes of early childhood caries. (Continued).
39. **Roblejo HB**. Clinical-epidemiological surveillance of microcephaly and other congenital defects after infection by Zika in pregnant women, products of conception and Cuban newborns. (Continued).
40. **Roblejo HB**. Community strategy for the promotion-prevention of genetic health in primary health care. (Continued).
41. **Roblejo HB**. Location of genetic susceptibility markers associated with the origin of schizophrenia in the Cuban population. (Continued).
42. **Seven M**, Paşalak İŞ, Bağcivan G. Genetics, biomarkers and symptoms during the trajectory of breast cancer: Sytematic review of literature. (Summit helped focus on high-risk women/individuals with genetic pre-disposition to cancer and development of strategies for risk reduction; integrated genetics into behavioral research, biomarkers and strategies for management of patient's symptoms).
43. Sjarif DR, **Ariani Y**, Priambodo R. mRNA identification method to detect IDS gene defect in Indonesia type II MPS patients. (Continued, project was inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).
44. Sjarif DR, **Ariani Y**, Priambodo R. Variant analysis of galactosamine (N-Acetyl)-6-Sulfatase (GALNS) Gene in Mucopolysaccharidosis IVA patients in Indonesia. (Project was

inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).

45. Sjarif DR, **Ariani Y**, Priambodo R. Variants analysis of GBA gene in Indonesian Gaucher disease patients. (Continued, project was inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).
46. Sjarif DR, **Ariani Y**, Priambodo R. Variant analysis of IDS gene in 30 Mucopolysaccharidosis type II patients. (Continued, project was inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).
47. Sjarif DR, **Ariani Y**, Priambodo R. Variant analysis of PTS gene in PKU. (Continued, project was inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).
48. Sjarif DR, **Ariani Y**, Yuliarti K, Hafifah CN. Genotype-phenotype analysis of type II MPS patients from Indonesia. (Continued, project was inspired by Summit lectures on Inborn errors of metabolism, Tools for molecular genetics, Diagnostic odyssey, Variant nomenclature and interpretation).
49. **Uwineza A, Hitayezu J**. Genetic etiology of epilepsy in Rwandan patients with intellectual disability. (Knowledge gained from Summit helped include microdeletion, microduplication of genes; helped organize writing of scientific paper).

## **F. Other Accomplishments/Initiatives:**

### 2018 Batch

1. **Abdulkareem FB**. Reviewer for NIH-sponsored Year 05 Mentored Research Applications for BRAINS (Building Research and Innovations in Nigeria's Science), University of Lagos (Nigeria, Jul. 2019); Abstract reviewer & facilitator for African Organization for Research & Training in Cancer Conference; Awarded 'Award of Excellence' by Faculty of Basic Medical Sciences, College of Medicine University of Lagos for contribution to research at the 5<sup>th</sup> Annual Scientific Conference (Oct. 2018); Attended Consortium of Universities in Global Health, Chicago (USA, Mar. 2019); Sponsored to attend Annual NCI/Fogarty International Program U54 Consortia Meeting on HIV-Associated Malignancies in Low-and Middle-income Countries (Tanzania, Mar. 2019); Invited speaker annual consortium meeting of the African Research Group for Oncology, presented on 'Update on the pathogenesis of colon cancer in Nigeria and future directions' (Nigeria, Apr. 2019); Presented on 'Colorectal cancer molecular subtypes by immunohistochemistry in a patient cohort from Nigeria', at ASCO Annual Meeting (USA, Jun. 2019); Invited speaker Global Oncology Summit (USA, Aug. 2019), presented on 'Point of care technologies in cancer diagnosis-the Nigerian experience'; Included cancer genetics/genomics in Pathology curriculum for MBBS/BDS; Founded, registered an NGO-FAJIM Medicare Foundation (<https:fajimmf.org.ng>) to improve health in underserved communities through health education, free medical checkups for non-communicable diseases; Initiated registry for congenital abnormalities; Identified patient with clinical, radiological features suggestive of Melorheostosis, managed by surgery, referred for counseling; Initiated documentation of cases of congenital abnormalities diagnosed at autopsy; Diagnosed cases (8) of congenital

anomalies at autopsy- tetralogy of Fallot (2) , VSD cases (2) with Eisenmenger's complex in one, tracheoesophageal fistula with malrotation (2) with ASD in one, Cleft lip and palate (1), multiple congenital anomalies in premature neonate (1).

2. **Adewole OO.** Lectured in genomics to medical students; Emphasized role of genomics in personalized care; Trained colleagues to establish research/clinical facilities.
3. **Adeyemo TA.** Facilitator at Genetic counseling course/workshop for Sickle Cell Disorder, Sickle Cell Foundation of Nigeria (May. 2019), delivered 4 lectures (Hemoglobinopathy: Definition and Types, Exchange Blood Transfusion, Basic Principles of Laboratory Diagnosis of Sickle Cell Disease and Practical Steps in Genetic Counseling); Mentored 7 junior faculty, College of Medicine University of Lagos and Lagos University Teaching Hospital; One awarded a seed Grant for 'Feasibility and Acceptability of New born and Early Infant (6 weeks) screening for Sickle Cell Disease in Nigeria; A pilot study in a local government area in Lagos State, Nigeria'; Established a Sickle Cell Disease Registry, Nigeria- targeted 5000 SCD entries for epidemiological studies; Facilitated World Bleeding Disorder Registry-enrolled 44 patients, improved access to replacement therapy and quality of life, established support and advocacy group meetings; Summit helped affirm the usefulness of data and registries for genetic epidemiological studies.
4. **Cornejo-Olivas M.** Part of Faculty team of the 10th MDS-PAS School for Young Neurologists (Peru, Nov. 2018); Invited to be reviewer for Neurogenetics chapter, Frontiers in Neurology Journal (opportunity due to improved scientific writing skills gained during the Summit); Organized with **M. Dueñas-Roque** (fellow Summiteer) and participated in I Curso Internacional de Genética Médica Genéticay Genómica Humana en Perú: Actualidad y perspectivas" (First Peruvian Congress on Medical Genetics, Peru, Jul. 2019); 2018-2019 LEAP Leadership fellow for International Society of Parkinson disease and other movement disorders (MDS)- an opportunity to improve leadership skills and share knowledge acquired during Summit on genetic variant nomenclature; Involved in MDSgene taskforce, an international effort to compile systematic review of every genetic disorder associated with abnormal movement disorder; Mentor for Northern Pacific Global Health Research Fellows Training consortium (FIC/NIH).
5. **Daich Varela M.** Awarded Clinical fellowship in Ophthalmic Genetics (NEI/NIH, 2019-2020, Summit influenced selection); Presented poster on 'Goldenhar Syndrome', Argentinian Ophthalmology Congress (Argentina, Jun. 2019).
6. **Das S.** Started as senior resident in Department of Medical Genetics, Christian Medical College Hospital, Vellore, India (Nov. 2018), selected as postdoctoral fellow (Clinical Genetics) for 2 years (Jul. 2019); Presented poster on 'A descriptive case series of ataxia telangiectasia (AT) from India', at 7<sup>th</sup> International Conference on Rare & Undiagnosed Disease (India, Apr. 2019); Awarded travel grant by The International Parkinson and Movement Disorder Society, presented poster on 'A descriptive study with molecular and cytogenetic analysis in patients of ataxia telangiectasia(AT) from the Indian subcontinent' (France, Sept. 2019); Identified, diagnosed and counselled patients (410) with various genetic disorders; Referred to specialty departments for interdisciplinary management; Involved in neuromuscular and perinatal clinic for patient management; Volunteered with Organization for Rare Diseases India (ORDI).
7. **Dueñas-Roque M.** President, Peruvian Society of Medical Genetics (2017-2019) and of Research and Innovation committee of Colegio Médico del Perú; Organized with **M. Cornejo-Olivas** (fellow Summiteer), first Medical Genetics meeting (Peru, Jul. 2019), first

course for young medical doctors of Lima (national broadcast via institutional Facebook page of the Colegio Médico del Perú, Peru, Jul. 2019; 5900 hits); Invited Dr. Muenke as speaker on ‘Holoprosencephaly, Craniosynostosis syndromes, Genetics syndromes in diverse populations’ and ‘How to write a scientific paper’; Used materials and resources from the Summit to organize the event.

8. **Dutta AK.** Secured new position as Assistant Professor at All India Institute of Medical Education (AIIMS, Kalyani, Jul. 2019, Summit significantly impacted the selection); Used training materials from the Summit for presentations on ‘Cell-free DNA in Prenatal Testing’, organized by Association of Medical Biochemists, India; Summit helped design curriculum for graduate medical education programs at AIIMS; Summit instilled zeal to establish, maintain patient registries for rare inherited disorders at National Institute of Biomedical Genomics (NIBG), coincided with Indian National Rare Disease Registry launched by Indian Council of Medical Research (ICMR); NIBG to contribute to the National Registry and provide understanding on burden of inherited rare diseases in India, with focus on research and natural history studies; Achieved accreditation for molecular diagnostic services for NIBG from European Molecular Genetics Quality Network (EMQN) (lab id 2279; NCBI Gene Test Registry <https://www.ncbi.nlm.nih.gov/gtr/labs/506786/>); Diagnosed patients (578) with rare genetic disorders (chromosomal, neuromuscular and hematological), referred from 20 medical schools; Provided pre-test/ post-test counseling; Referred patients for management; Significantly impacted reproductive decision making, utilization of prenatal diagnostic services and ended ‘diagnostic odyssey’ for patients; Enrolled families in clinical trials for Duchenne Muscular Dystrophy (PTC therapeutics), charitable programs for enzyme replacement (Genzyme) and exon skipping therapy (Spinraza) in India; Measures permitted patient support groups (Organization of Rare Diseases India (ORDI) and PWS/ Angelman Society of India) to help patients.
9. **Dwivedi A.** Completed Doctorate in Medicine from SGPGIMS (India); Joined as Assistant Professor at Army Hospital Research and Referral (New Delhi, Jul. 2019); Presented on ‘Outcome of Enzyme Replacement Therapy in Gaucher disease’ (USA, Sept. 2019), at International Society of Inborn errors of Metabolism Conference; First Medical Geneticist at Armed Forces Medical Services in India; Initiated establishment of Genetics- clinic, OPD services, Counseling, Core Genetics lab (cytogenetic, molecular, NGS platforms); Knowledge from Summit helped conceptualize, design first Medical Genetics Centre for Indian Defense Services in management and counseling of patients with genetic disorders (holoprosencephaly, craniosynostosis syndromes, frontonasal dysplasia, lysosomal storage disorders etc.); Materials from Summit helped educate fellow residents and researchers.
10. **Edem-Hotah J.** Invited by **J. Gitaka** (fellow Summiteer), to attend African Academic of Sciences Maternal, Neonatal and Child Health (MNCH) Workshop (Kenya, Jun. 2019) to discuss research priorities, leadership, policy in Africa; Genomics research was emphasized to inform on reduction of maternal, neonatal and child mortalities in Africa; Attended the American Society of Hematology African New-born Screening Program and Early Intervention Consortium Meeting (S. Africa, Jul. 2019), to add Sierra Leone to the consortium for support of sickle cell disease research program; Presented posters on ‘Model for early detection of sickle cell disease in rural African community healthcare settings’ and ‘Early diagnosis and genetic counseling for sickle cell disease across the care pathway in limited-resourced community health clinics’, at ICM Regional Workshop Conference (Namibia, Sept. 2019); Included lectures from Summit in curriculum at University of Sierra

Leone (USL) College of Medicine of Medicine and Allied Health Sciences, Faculty of Nursing; Observed increased interest and awareness for genetics and genomics training among faculty and nursing students; Planned with faculty and discussed with administrators need to introduce a course in Diploma in Genetics and Genomics Counseling at the Faculty of Nursing.

11. **Eshete MA.** Chair, Surgical Department Research Ethics Committee, supported residents and faculty members in research; Presented on ‘The role of Environmental Factors in the occurrence of orofacial clefts in the Ethiopian Population’, at annual assembly of Ethiopian Society of Plastic and Reconstructive Surgeons; Used materials from Summit for seminars and lectures for faculty members and residents; Shared knowledge with fellows and residents from different universities who visited for short and long-term study; Upgraded cleft registry database, registered newborns and adults with orofacial clefts (>250); Cleft patients (> 300) received multidisciplinary cleft care in collaboration with Smile Train and Transforming Faces; Improved quality of life for cleft patients (100) and their parents because of full rehabilitation and ability to speak intelligibly and smile etc.
12. **Gitaka J.** Included genomics in Biomedical curriculum at Kerinyaga University with help of **S. Mburu** (fellow Summiteer); Developed the Mary Help Hospital Congenital Diseases System for recording, tracking and monitoring congenital birth defects, genetic diseases; Identified, diagnosed and treated cases (11)- Down syndrome (3), Congenital Talipes Equino Valus (CTEV, 8); Referred cases (5 CTEV) for counseling and medical management; Patients and families (11) reported improvement in quality of life due to correct diagnosis and pathway to care.
13. **Kemevor-Asima D.** Involved in Workshop in Genetics, Department of Child Health, Korle Bu Teaching Hospital (Dec. 2018); Organized symposium on ‘Genomics and Rare Diseases’, Rare Disease Ghana in collaboration with West African Genetic Medical Centre, to increase clinicians’ awareness on genomics and relevance in patient care, presented on ‘Non-invasive prenatal screening and newborn screening’ (Feb. 2019); Invited to join a team of researchers and clinicians to start a registry on congenital anomalies, genetic disorders and rare diseases in Ghana.
14. **Lertwilaiwittaya P.** Completed internship in Internal medicine; Started as Attendant in Medical Genetics Clinic, Department of Medicine, and in Molecular Genetics Laboratory, Department of R&D, Faculty of Medicine Siriraj Hospital, Mahidol University, Thailand (Feb. 2019); Reviewed manuscript for Mol Genet Genomic Med.; Introduced, promoted usage, enrolled Mahidol University in OMIM and ClinVar databases; Interpreted dementia patients (64) using NGS panel (ACMG classification), for use in research and clinical utility; Involved in clinical whole exome sequencing interpretations in pediatric neurology (2), pediatric endocrinology (1), metabolic bone (1), adult neuro-ophthalmology (1)); Participated on Intersex Conference Board (disorders of sex development); Enrolled patients (300) with the Collaborative Aging and Dementia Research Society Thailand (CART, <https://cogdementiathai.com/?locale=en>), a web-based uniform data set for neurodegenerative dementia cases, analyzed samples (40) with NGS.
15. **Mburu S.** Included Medical Genetics and Genetic Counseling in graduate school (M.Sc.) curriculum (pending University’s Senate approval, Sept. 2019); Introduced, strengthened, expanded medical genetics research and scope, and bioinformatics to include anti-inflammatory diseases and mitochondrial disorders etc., at School of Health Sciences, Kirinyaga University (KyU); Presented report on Summit to University faculty and

- administrators, emphasized importance of medical genetics research, big data analysis, precision medicine; Made recommendations for path forward; Emphasized the need for computational tools in big data analysis and importance of electronic health records to undergraduates; Trained and mentored junior staff (2) on medical genetics and ethics in research; Established basic facilities for molecular techniques, cytogenetics, immunohistochemistry (IHC), cell cytotoxicity testing at KyU and KAVI-ICR.
16. **Messaoud O.** On jury for first PhD thesis in Biology, (Mauritania, Dec. 2018); Reviewed papers for new journals (Clinical genetics; Molecular Genetics and Genomic Medicine; Gene; Journal of European Academy of Dermatology Venereology); Member, Arab-German Young Academy of Sciences and Humanities Working Group 'Health and Society' (<http://agya.info>); Awarded Idea Competition Prize for 'Raising awareness on rare diseases' (Oct. 2018); Participated in Science Communication training on 'How to Integrate Storytelling in your Communication Style' (Egypt, Oct. 2018); Invited speaker International Symposium on Xeroderma Pigmentosum and other Nucleotide Excision Repair Disorders, presented on 'Clinical and genetic investigation of Xeroderma pigmentosum in Tunisia: current situation and perspectives' (UK, Mar. 2019); Organized Rare Disease Day (Tunisia, Mar. 2019); Participated in training on 'Intercultural team-building' (Germany, Apr. 2019); Participated in workshop on Maternal Neonatal Health, organized by African Academy of Sciences, the UK Academy of Medical Sciences and Bill & Melinda Gates Foundation (Kenya, Jun. 2019); Participated in workshop on 'Introduction to open science', Institut Pasteur de Tunis, (Tunisia, Jun. 2019); Participated in workshop on 'From Traditional to Innovative Active Methods in Higher Education' (Tunisia, Jul. 2019); Invited speaker at Phi's Research and Innovation Summit, presented on 'Biology in the era of Big Data' in plenary session on Bioethics of Gene editing, Stem Cells & Big Data in Research and Therapy (Jordan, Aug. 2019); Member, DNA Repair Interest Group (<http://sigs.nih.gov/DNA-repair>); Used resources from Summit for lecture on Human Genetics, at Faculty of Medicine of Tunis; Shared Summit lectures with researchers, post-docs and PhD students.
  17. **Mistri M.** Scientist (Inherited Genomics) at Neuberger Centre for Medical Genetics (Gujarat, India); Awarded travel grant by Society for the Study of Inborn Errors of Metabolism (SSIEM) for symposium (Greece, Sept. 2018); Co-author on poster 'Mutations in PPA2 gene as a cause of sudden unexpected cardiac arrest in a Chilean family, with N. **Nakousi-Capurro** (fellow Summiteer), Chilean Genetics Society meeting, (Chile, Nov. 2018); Worked with NovaSeq NGS platform (first one in Gujarat, second in India); Involved in NGS based diagnostic services (Clinical exome, Whole exome study) for rare and common genetic disorders.
  18. **Muttamba W.** Personalized/advanced training at Summit in 'Principles of Biobanking' at NHLBI, provided knowledge in shipment and biobanking of samples from other countries, for the African Severe Asthma Project (ASAP) and H3A Africa Biorepository; Assisted with DNA extraction at Medical and Molecular laboratory within the University.
  19. **Naeem MA.** Member of organizing committee, participated in 3<sup>rd</sup> International Symposium on Advances in Molecular Biology of Plants and Health Sciences (Pakistan, Dec. 2018); Summit helped improve Medical Genetics curriculum; Trained undergraduate and graduate level students (M.Sc.) from Islamia University Bahawalpur and Sardar Bahadur Khan Women's University, Quetta, Pakistan, in human genotyping and Sanger sequencing based on advanced training received during the Summit.



20. **Nakousi-Capurro N.** Completed second year Medical Genetics resident training, University of Chile; Collaborator with the new Undiagnosed Diseases work group, Human Genetics Branch, Biomedical Sciences Institute, University of Chile; Presented poster on ‘Mutations in PPA2 gene as a cause of sudden unexpected cardiac arrest in a Chilean family, at Chilean Genetics Society (Chile, Nov. 2018); Presented Clinical meetings on- CNVs in Inborn Errors of Metabolism, at National Institute of Food Technology (Chile, Apr. 2019), Turner Syndrome in Neonatology, at San Borja Arriarán Clinical Hospital (Chile, Jun. 2019), Genetic tests in the clinical setting, at San Borja Arriarán Clinical Hospital (Chile, Jul. 2019); Shared knowledge obtained at Summit with colleagues and students; Technical knowledge acquired during the Summit helped provide better clinical evaluations to patients, resulting in improved quality of life for patients and families.
21. **Olojede OC.** Presented poster on ‘Odontogenic Tumours: Pattern seen at a Nigerian Tertiary Institution in relation to the latest W.H.O. Classification’, at International Association for Dental Research, IADR/AADR/CADR (Canada, Jun. 2019).
22. **Ottaru S.** Committee Member of Tanzania Society of Human Genetics; Member of Genetic Society of America; Registered for Online self-paced course on Birth Defects Surveillance and Prevention organized by International Clearing House for Birth Defects; Submitted protocol for Genetic Counseling services to Catholic University of Health and Allied Sciences, Mwanza, Tanzania; Collaborated with **A. Mgasa**, **L. Malasa** (2018, 2016 Summiteers) to establish pilot Congenital Birth Defect registry in 3 regional referral hospitals in Dar es Salaam; Registered, diagnosed cases (13), referred them to Muhimbili National Hospital for management and surgeries.
23. **Savina O.** Completed specialization in Medical Genetics from Shupyk National Medical Academy of Postgraduate Education (Mar. 2019); Presented on ophthalmogenetics in Aniridia and WAGR syndrome management at round-table meeting of Ukrainian ophthalmologists (Ukraine, May. 2019); Presented on ‘Genetic diagnostics of retinoblastoma’, at International Applied Science Conference-Filatov’s lectures (Ukraine, May. 2019); Presented on ‘Peculiarities of visual organs for improving quality of teaching children with eye pathologies’, at Social and Pedagogical Partnership Conference (Ukraine, Jun. 2019); Honorary member of all-Ukrainian NGO ‘Association of tiflopedagogues of Ukraine’; Initiated introduction of an ophthalmogeneticist position at ISIDA-IVF clinic (pending approval).
24. **Taiwo O.** Appointed member, Research and Training Committee of Intercountry Center for Oral Health for Africa (Nigeria, May. 2019); Invited speaker, presented on ‘Maintaining Good Oral Hygiene in Crisis Situations’ at Annual General Meeting of the Medical Women’s Association of Nigeria (Nigeria, Nov. 2018); Invited speaker, presented on ‘Contingency Table Analysis’ and ‘Choice of Statistical Test for Data Analysis’, at 15<sup>th</sup> Annual Scientific Conference of the International Association for Dental Research (Nigeria Division, Nov. 2018); Lectured on Research Appreciation at Department of Surgery, Jos University Teaching Hospital, Nigeria; Conducted two-day training on ‘Research Methodology’ for professional staff of Oral Health Advocacy Initiative, included courses on Introduction to Research Methodology, Development of a Research Title, Research Questions and Hypothesis, How to do a Literature Review, Research Designs, Sample Size Determination, Sampling Techniques, Variables and Measurement Scales, Data Collection and Questionnaire designs, Choice of Statistical Tests for Data analysis, Descriptive Statistics (Nigeria, Jun. 2019).

25. **Utumatwishima JN.** Initiated 'Face2gene Club', screened undetected congenital malformations in Rwanda (knowledge acquired on Face2gene from Summit); Transferred children (15) with Down syndrome to Rwanda Military Hospital.
26. **Wangi KYW.** Invited speaker on 'Prenatal and Newborn Genetics Screening', at Essential Neonatal Care Optimization Symposium & Workshop (Indonesia, Feb. 2019); Developed undergraduate nursing curriculum at Tarumanagara School of Health Sciences (2019), courses included Trend and Issues in Nursing; Mentored students (2) after completion of course; Introduced 3 topics for class meetings in genetics and genomics (Precision Medicine, Prenatal and Newborn Genetics Screening, Genetics Counseling in Nursing).

2017 Batch

27. **Abad PJ.** Organized forum 'Omics in Nursing' with Dr. L. Saligan (NINR/NIH) as resource speaker (Sept. 2018); Shared roles of genetic counselors in Asia at Summer school, Asia Pacific Society of Human Genetics (Nov. 2018); Served as resource person on genetic counseling for web-based resource for health professionals and parents in pediatric cancers (University of the Philippines Open University, funded by Philippines Department of Science and Technology).
28. **Avogbe PH.** Promoted to Associate Professor at University of Abomey-Calavi, Benin (Jul. 2019); Worked as Visiting Scientist, Genetic Cancer Susceptibility Group, International Agency for Research on Cancer/WHO, France; Invited speaker for Molecular Biomarkers and Cancer Research Symposium, University of Abomey-Calavi (Benin, Jun. 2019); Lectured on Genetic basis of disease, Next-generation sequencing methods, Cancer genetics and genomics to graduate level students, University of Abomey-Calavi; Used resources from Summit to include genomics in research curricula.
29. **Benítez Cordero YB.** Speaker at 50<sup>th</sup> Annual Meeting of ECLAMC and 3<sup>rd</sup> Annual Meeting of RELAMC (Argentina, Nov. 2018), presented on 'Cuban Registry of Congenital Malformations- General aspects of its operation and considerations for the Basic Manual of RELAMC'; Lectured in Genetic Counseling at graduate level (M.S.), National Center of Medical Genetics, Venezuela; Summit helped update topics in genetics and provided tools for genetic counseling; Mentored residents (2) in clinical genetics; Member of International Clearinghouse for Birth Defects Prevention & Research; Evaluated genetic disorders (52) of either monogenic, chromosomal or multifactorial etiology; Codified cases (3000) for the registry; Referred cases (12) for genetics analysis and medical management (2 Congenital Myopathy, 1 Erdheim-Chester disease, 9 infertile couples (3 thrombopathy, 2 Turner Syndrome, 4 with DNA fragmentation in spermatozoa)).
30. **Casado PL.** Reviewer for Archives of Oral Biology, International Journal of Growth Factors and Stem Cells in Dentistry, Brazilian Dental Journal and POS ONE (2018-2019).
31. **Dhoro M.** Updated graduate school curricula and research based on materials obtained at the Summit; Lectured on Genetic basis of disease and gene therapy, Diagnosis of genetic disorders, Genetic counseling, Genomic medicine and Pharmacogenetics to graduate level clinical pharmacology students (medical doctors, postgraduates); Reference materials and contacts from Summit increased knowledge, improved supervisory skills; Generated interest in genomics research among undergraduate and graduate students; Mentored graduate level students (M.Phil., D.Phil. Clinical pharmacology) on research projects; Used resources from the Summit (text book 'Smith's recognizable patterns of Human Malformation, 7<sup>th</sup> Edition'), to identify congenital disorders at Parirenyatwa Hospital, Zimbabwe and provide baseline

data for larger studies; Developed Biobank register and database on genomic studies to support genomics research at University of Zimbabwe, College of Health Sciences.

32. **Díaz C.** Graduated as a Clinical Geneticist (2019); Attended VI Latin American course on Lysosomal Storage Diseases organized by Genetic Institute For All and SHIRE (Chile, 2019); Coordinator of course 'Bridging the gap between Genomics and the Clinic-Experiences in Neurology and Psychiatry' (University of Chile, Santiago), presented on 'Experiences in diagnostic applications of Genomics in Chile'.
33. **Fatima SS.** Recipient of Dean's Award for 'Excellence in Research', Aga Khan University (Dec. 2018); Invited speaker on 'Influence of Perinatal Environment over fetal programming for metabolic syndrome', at 2<sup>nd</sup> Annual Research Talk (ART), University of Karachi (Pakistan, Sept. 2018); Presented on 'Molecular Basis of Nonalcoholic Fatty Liver Disease and Metabolic Syndrome in a South Asian Population', at 6<sup>th</sup> Biennial South Asian Association of Physiologists and 16<sup>th</sup> Biennial Pakistan Physiological Society Conference (Pakistan, Dec. 2018)- received Best Paper Award; Invited speaker on 'Health at Every Size; the Hidden Facts of Obesity Paradigms in Pakistan', SZABIST, BARS Symposium (Pakistan, Apr. 2019); Conducted research conference for undergraduate medical, nursing and biomedical students; Emphasized role of good protocol writing and need for inclusion of genetics and genomics in research and health care in low resource settings; Supervised graduate level students (4).
34. **Hitayezu J.** Invited speaker on 'Down syndrome: Medical approach' at World Down Syndrome Day organized by Rwanda Down Syndrome Organization (Rwanda, Mar. 2019)- Theme: 'Leave no one behind'.
35. **James O.** Lectured on Genetics of Craniofacial Malformations to head and neck surgeons at AOCMF Seminar on Congenital Deformities of the Craniofacial Region: Basic and Advanced Management (Nigeria, Jun. 2019); Performed cleft repair surgeries (25).
36. **Lotz-Esquivel S.** Started 3 month Clinical Clerkship in Medical Genetics and Metabolism Department, National Children's Hospital (Costa Rica, 2019); Attended 3<sup>rd</sup> PAC Summit Rare Diseases & Master Class XLSD – Sanofi Genzyme (Ecuador Apr. 2019); Attended 1<sup>st</sup> Expert Meeting in Phenylketonuria, Central America and Caribbean – Biomarin (Panamá, Jun. 2019); Aided in establishing first Multidisciplinary Adults' Clinic for Rare and Orphan Diseases in Latin America, Hospital San Juan de Dios (Costa Rica, 2018), a national reference center for adolescents and adults with genetic and metabolic conditions; Expanded database, managed new cases and follow-ups (160) with 60 different diagnosis (disorders of carbohydrate, mitochondrial energy, and protein metabolism, dyslipidemias, porphyrias, lysosomal storage diseases, and other miscellaneous conditions); Referred patients to other specialty departments; Trained hospital staff in different departments; Identified new cases (8) through newborn screening, diagnosed and treated with help from materials provided at the Summit; Helped transition patients to adult clinics; Promoted research and knowledge to colleagues; Consolidated multidisciplinary care, resulted in better patient management, improvement in quality of life of patients and families, and strengthened the public healthcare system.
37. **Mahfoudh W.** Selected to review abstracts for 12<sup>th</sup> International AORTIC Cancer Conference (Mozambique, Nov. 2019); Received financial support from CRDF Global to participate in 7<sup>th</sup> Annual Symposium, Global Cancer Research on Translation and Implementation for Impact in Global Cancer Research, organized by NCI, the University of

Chicago Cancer Center, and the Consortium of Universities for Global Health (CUGH) and to attend the 10<sup>th</sup> Annual CUGH Global Health Conference (USA, Mar. 2019).

38. **Maure Pizarro P.** Finished residency, started work at Hospital Exequiel González Cortés (Pediatric Hospital); Attended courses- III School of Clinical Genomics, University of Buenos Aires (Argentina, Aug. 2018), NGS in Clinical Genetics and research: Analysis and Interpretation of data, Catholic University of Chile (Chile, Nov. 2018); Participated in Scientific Day 'Improving the quality of life of patients with diagnosis of mucopolysaccharidosis in Chile' (Chile, Dec. 2018); Participated in National Registry of Congenital Anomalies (RENACH, Chile); Collaborated with countries in S. America on Latin American Collaborative Study of Congenital Malformations (ECLAMC), emphasized need to complete the implementation of the registry; Initiated a cytogenetics lab; Integrated learnings from the Summit to attain similar standards of practice in genetics to improve patient care, management of condition and quality of life.
39. **Mehrez MI.** Accepted for Continuing Education Fellowship Program in Craniofacial Genetics at University of Kentucky (USAID program, Jan. 2019); Presented on 'Early diagnosis of genetic disorders through oro-dental anomalies' in a secondary school to educate girls in basics of genetics (Mar. 2019); Presented on 'Research Cookbook' on Scientific Day of Oro-dental Genetics Department, National Research Centre (Egypt, Apr. 2019); Presented an e-poster 'Mandibulacral Dysplasia type A: An Oro-dental Perspective' at European Society of Human Genetics Conference (Sweden, Jun. 2019); Identified Blood disorders (45) and genodermatoses (15); Referred cases (4) for management of dental condition; Provided oral rehabilitation with prosthodontics to patients, resulting in improved quality of life and psychological well-being; Explained importance of genetic counseling as a profession based on Summit learnings; The Summit resulted in a collaboration with Baylor-Hopkins.
40. **Mgasa A.** Applied for early-career Scientist Leadership Program to Genetic Society of America; Submitted two abstracts for 9<sup>th</sup> International Conference on Birth Defect and Disabilities in the Developing World (Sri Lanka, Mar. 2020); Enrolled in Online Self-paced Course on Birth Defects Surveillance and Prevention organized by International Clearing House for Birth Defects; Collaborated with **S. Otarru, L. Malasa** (2018, 2016 fellow Summiteers) to establish a pilot Congenital Birth Defect registry in 3 regional referral hospitals in Dar es Salaam, Tanzania; Collaborated with pediatricians in regional hospitals for management of affected neonates and families, monitoring of registry; Trained Labor, Neonatal and Pediatric ward staff on identification of congenital birth defects, registration; Diagnosed cases (13), neonates referred to National Hospital for medical/surgical management; Resulted in improved quality of life of affected individuals and their families.
41. **Otaify GA.** Presented poster on 'Challenges in the Management of Metabolic Bone Disorders and Pitfalls to Avoid', at 15<sup>th</sup> Middle East Metabolic Group meeting (Lebanon, Nov. 2018); Presented on 'Genotype of Bruck syndrome with phenotype of Osteogenesis Imperfecta, separate syndromes or expansion of the spectrum', at European Society of Human Genetics (Sweden, Jun. 2019); Obtained scholarship to attend the 14<sup>th</sup> Goldrain course on Clinical Cytogenetics (Italy, Aug. 2019); Lectured in the 3<sup>rd</sup> Basic Course of Human Genetics on 'Phenotypic variation in relation to gene alteration at National Research Centre, Egypt; Lectured a course on Basics of Human Genetics, to undergraduates in Faculty of Physiotherapy, Cairo University, Summit helped structure lectures; Lectured nursing faculty and students, Cairo University on 'Genetic disorders- importance of early detection, management and preventive measures', as part of Community Awareness Program initiated

by Human Genetics and Genome Research Division and implemented goals of Summit; Improved Outpatient consultation, management and counseling for patients with different genetic diseases; Started a registry with few registrations (to be increased after training of personnel); Identified patients (425) with genetic diseases or congenital birth defects (345 skeletal malformations, 26 couples with previous affected births, 54 other genetic disorders); Referred these cases for counseling and management; Treated 40 of the 70 MPS cases with ERT, new cases of osteogenesis imperfecta (22) with bisphosphonate, and cases (15) of hereditary rickets.

42. **Owusu M.** Dr. Muenke's visit (Dec. 2018) initiated process for study on genetics of congenital heart disease at Komfo Anokye Teaching Hospital, Ghana.
43. **Petlichkovski A.** Presented on 'Possibilities and Challenges in Diagnosing Rare diseases' (Macedonia, Feb. 2019) organized by National Alliance for Rare Diseases, supported by the Ministry of Health; Included Summit lectures and data in curriculum at Medical Faculty; Proposed new program for specialization in clinical laboratory genetics (inheritance, diagnosis and treatment of genetic conditions) in cooperation with institutions in genetics, in Macedonia; Program would be recognized in Europe; Summit helped build picture of a functional entity- talks advanced in development of curriculum in genetics with other institutions, conducted preliminary talks with health authorities to merge testing, diagnosis, treatment and counseling under a single institution; Routinely used NGS platform for population-based HLA typing; Performed genetic testing on couples (170 ) diagnosed with recurrent spontaneous abortion; Referred these cases for genetic counseling.
44. **Nandal R.** Presented on 'Cardiovascular genetics – the new and evolving', at 13<sup>th</sup> Indian Society of Cardiology Conference (India, Dec. 2018); Conducted weekly congenital heart diseases clinics; Initiated, maintained a congenital heart disease registry; Initiated, streamlined use of facial dysmorphism recognition tools in dysmorphic patients with congenital heart diseases; Identified cases of Noonan syndrome (8), Marfan syndrome (3), William syndrome (3), Di Georgi syndrome (2); Referred these patients for genetic counseling; Referred other patients (~50) with congenital heart diseases and undiagnosed with facial dysmorphic recognition tools, to a clinical geneticist; Identified families (3) with autosomal dominant hypertrophic cardiomyopathy; Referred these families for genetic testing; Routinely established systems for detailed family history, pedigree analysis of patients with familial hyperlipidemia and young myocardial infarction.
45. **Roy S.** Speaker at 46<sup>th</sup> Annual Conference of Bangladesh Ophthalmological Society (Bangladesh, Mar. 2019) on 'Probing is more Effective as a Treatment Option in Complicated Congenital Nasolacrimal duct Obstruction'; Speaker at 34<sup>th</sup> Asia Pacific Academy of Ophthalmology (Thailand, Mar. 2019) on 'Establishing RB Center in a Tertiary Eye Care Center of Bangladesh – A New Hope for Retinoblastoma Patients'; Speaker at 6<sup>th</sup> Biennial conference of Bangladesh Oculoplastic Surgeon Society (Bangladesh, Jun. 2019) on 'Surprises in Pandora's Box- Atypical Cases of Orbit'; Introduced basics of Genetics and Genomics in B.Sc. (Optometry) curriculum; Introduced two CME programs (Basics of Ocular Genetic Diseases; Recent Management Protocol), at the hospital; Identified genetic disorder cases (75), treated patients (56), referred for medical management (19), patients (43) satisfied with their outcome.
46. **Thakur N.** Initiated curriculum in Pathology, Clinical genetics in residency program; Designed 15 day course in Clinical Genetics for faculty and residents at NAMS (pending approval from Academic Council); Established first sequencing center in Nepal; First tests

to be launched- Non Invasive Prenatal Testing, Aneuploidy screening in product of conception, Pre-implantation genetic screening, Cancer hotspot testing for targeted therapy, Germline mutation testing for BRCA1/BRCA2; Established double/triple/quad hormonal testing for prenatal screening; Worked with NAMS and Ministry of Health to establish a clinical geneticist position through examinations; Summit helped improve patient care along the care continuum, number of patients increased 2-fold; Diagnosed new cases (397- 247 new karyotypes with 30 new anomalies).

47. **Tolegen N.** Attended scientific and practical conference on Neuromorphology, at National Medical Research Center of Neurosurgery (Russia, May 2019); Karyotyped pregnant women (426) with suspected fetus abnormalities; Identified chromosomal abnormalities (45- 27 Down syndrome, 6 Patau syndrome, 5 Edwards syndrome, 2 Turner syndrome, 5 structural chromosomal abnormalities); Neuromuscular disease (Duchenne muscular dystrophy, muscular spinal amyotrophy, leukodystrophy) suspected in children (54) and fetuses (2); Molecular genetic testing of MLPA confirmed diagnosis in children (15) and fetus (1).
48. **Torres-Mejía G.** Invited speaker at APEC Conference on Smart Healthcare for Non-communicable Diseases and Their Risk Factors Prevention and Control, presented on 'Precision Prevention and Early Detection of Breast Cancer Using Genetic Markers Associated with Several Modifiable Established BC Risk Factors' (China, Apr. 2019); Presented poster on 'Genes regulating energy homeostasis modify the association between serum concentrations of IGF-1 and IGFBP-3 and breast cancer risk among premenopausal women: The breast health disparities study', at AICR Research Conference on Diet, Obesity, Physical Activity and Cancer: Beyond the Blueprint, (USA, May 2019); Invited speaker on 'Breast cancer in Mexican women, what have we learned?', in the Mammary gland pathology and Surgery course (Mexico, Jul. 2019); Identified (BRCA 1 or 2 mutations) in women (9) with breast cancer (PRECAMA study), sent results to geneticist; Due to importance of counseling emphasized at the Summit, added two geneticists to the staff at the hospital (PRECAMA study) and one at the local Institute.
49. **Tuncay FY.** Passed European Board of Ophthalmology and International Council of Ophthalmology Visual Sciences, Optics and Refraction Examinations; Presented as speaker on 'Knockin with CRISPR/Cas9 in zebrafish' at Qatar International Zebrafish Conference and Workshop (Qatar, Apr. 2019); Member of Asian Eye Genetics Consortium, Turkey.
50. **Vishnopolska SA.** Lectured two postgraduate courses- Human Genetics and School of Clinical Genomics; Participated in writing a grant for Precision Medicine from Agencia Nacional de Promoción Científica y Tecnológica (ANPCyT); Identified, diagnosed and treated a family with isolated growth hormone (GH) deficiency, newborn in family treated immediately with GH replacement therapy.
51. **Wayengera M.** Awarded PhD in Pathogen Omics (Jan. 2019); Selected finalist for WHO Innovation Challenge (Mar. 2019); Worked with Uganda Cancer Institute and partners for integrating genetic testing and counseling in cancer care through National Cancer Policy; Provided opportunity for integration of clinical and molecular genetics and genomics into the care of common diseases in Uganda and Africa; Identified, diagnosed treated patients (156) with congenital abnormalities; Involved in surveillance, control, prevention of the EVD outbreak in DR of Congo.
52. **Yousef YA.** Identified, diagnosed treated cases of Retinoblastoma (28); Referred patients (30) with familial and non-familial Retinoblastoma (genetic test positive) for counseling, management of condition; Improved quality of life of patients and families by informing

patients negative for germline disease, the extremely low risk of disease transmission to their off-springs.

2016 Batch

53. **Adeyemo AA.** Commencement of Universal Newborn Hearing Screening at University College Hospital, Ibadan.
54. **Adeoye AM.** Joint appointment with new Institute of Cardiovascular Diseases, College of Medicine, University of Ibadan, Nigeria; Head of the Molecular Cardiology and Preventive Cardiology Unit; Deputy Chairman, Medical Advisory Committee (Education and Training) at the University College Hospital, Ibadan, Nigeria, and the first Teaching Hospital in the country; As one of the World Heart Federation Emerging Leaders wrote application for inclusion of Dabigatran in WHO Emergency Medicine List (2019 EMLs), enlisted now as a new oral anticoagulant (NOAC) in prevention of stroke and thromboembolism for patients with atrial fibrillation and other hypercoagulable states.
55. **Adeyemo WL.** Awarded 2018 Nigerian Academy of Science (NAS) Gold Medal Prize in Life Sciences (highest honour bestowed on Nigerian Scientist, Jan. 2019); Coordinated Bioinformatics and Genomics Workshops for junior faculty at the College of Medicine University of Lagos, delivered lectures- Introduction to Genomics, Genomics and Other Omics, Techniques and Tools in Genomics, Introduction to Genome databases and SNPedia; Mentored junior faculty (7) awarded Seed Grant to execute research projects in genomics at the College of Medicine, University of Lagos.
56. **Ariani Y.** Presented on 'Identification of a Novel Mutation on Exon 6 of Iduronate-2-Sulfatase Gene in an Indonesian Patient With Mucopolysaccharidosis Type II', 2<sup>nd</sup> Physics and Technologies in Medicine and Dentistry Symposium (Indonesia, 2018); Developed Molecular Genetics, Population Genetics, Reproductive Genetics modules for graduate level (M.Sc.) Biomedical science students, Faculty of Medicine, University of Indonesia; Established Center of Excellence for Rare Diseases in Cipto Mangunkusumo National Referral Hospital, Jakarta; Promoted the MoU between Cipto Mangunkusumo Hospital and Human Genetic Research Center for free genetic testing for poor patients; Helped start registry for MPS I, Pompe, Gaucher disease, structural birth defects; Continued registry for MPS type II and type IVA; Documented, monitored enzyme replacement therapy for MPS II, MPS IVA, Gaucher and Pompe diseases; Empowered Indonesian Rare Disease Foundation to develop family support groups and patient monitoring.
57. **Deniz E.** Planned to establish a non-thesis introductory program in genomics at Department of Molecular Biology and Genetics, Acibadem University, Istanbul, Turkey, for medical doctors, biotechnologists and individuals curious in genomic data and its clinical utility; As a result of the Summit, supervised graduate level (M.Sc.) students (3) in genomics and genome editing projects.
58. **Ekure E.** Speaker at 1<sup>st</sup> Conference of the Special thematic Working Group on Maternal, Neonatal, Children and Women Health, on 'Managing Genetic Disorders in Childhood in Emerging Economies: Social, Ethical Financial, System and Family Implications', at University of Ibadan (Nigeria, Apr. 2019); Identified cases (318) of congenital heart defects at Lagos Teaching Hospital; All counseled and/or referred for medical management.
59. **Guio H.** Presented on 'Peruvian Genome Project: An opportunity to understand Peruvians and Latin People', at University of Chile (Chile, Dec. 2018) and Latinono American School

- of Medical and Human Genetics (Brazil, May 2019); Presented on 'Genetics and Genomics in Peru' (Luxemburg, Jun. 2019).
60. **Hussen DF.** Selected as Faculty in Egyptian Committee of Pathology Training (ECPT); Lectured on Basic Genetics at The National Research Centre (NRC), in collaboration with ECPT, (Egypt, Mar. 2019); As member of Community Awareness Committee in Human Genetics and Genomics Research Division, NRC (estab. Jan. 2018), payed monthly visits to rural areas of Egyptian governorates and secondary schools to raise awareness in genetic diseases.
  61. **Lallar M.** Faculty in DNB Medical Genetics super-specialty training program; Presented poster 'Exome sequencing identifies LICAM mutation in fetus with ventriculomegaly and agenesis of corpus callosum', at 4<sup>th</sup> ICBBD (India, Dec. 2018); Member organizing committee and session Chair on 'Turner Syndrome- Challenges across lifespan childhood, adolescence and adulthood- An Indo-US educational activity' (India, Jan. 2019); Presented poster 'Gaucher disease: Lessons learnt and insights in the natural history of treated and untreated patients', 5<sup>th</sup> ISIEM (India, Jan. 2019); Speaker on 'From Genetics to Genomics – An Obstetricians Perspective', at 25<sup>th</sup> Annual Conference NARCHI (India, Feb. 2019); Organizing Committee member and Speaker at 7<sup>th</sup> Conference of Undiagnosed Diseases Network International, presented on 'Mystery case- Severe failure to thrive, developmental delay and dysmorphism' and presented poster 'Noonan syndrome and related R A Sopathies: phenotypic and genotypic spectrum' (India, Apr. 2019); Involved in interdepartmental Medical Genetics teaching/training of physicians at SGRH, New Delhi; Identified new genetic cases (55), provided prenatal diagnosis (20), referred patients(25), for symptomatic treatment; Involved in follow up care of patients on ERT for LSD, and for improvement in quality of life; Started a Birth Defect Registry at the referral fetal medicine and diagnostic center.
  62. **Malasa L.** Undertook Online training on Human Subject Research: Collaborative Institutional Training Initiatives by Baylor College of Medicine (Jan. 2019); Attended training on Research Electronic Data Capture (REDCap) at Muhimbili University of Health and Allied Sciences (Mar. 2019); Awarded Global Health Fellowship, Novartis Institutes for BioMedical Research (USA, Jun. 2019).
  63. **Okafor F.** Promoted to Associate Professor of Nursing Science (back dated to 2017); Nominated, participated in the Accreditation of two Nursing Science Departments in Federal and State Institutions in Nigeria (Jun. 2019); Worked on Ph.D. dissertation 'Nursing Training Institutions' Lecturers' and Students' Reproductive Health Genetics and Genomics Knowledge, Beliefs and Practice in Edo State, Nigeria'; Enlisted as member of Global Genetic Nurses Alliance (G2NA) Group- participated in webinar conference (Jul. 2019); Presented on 'National Policy on Task Shifting and Sharing in Health Care Industry in Nigeria', at the National Association of Nigerian Nurses and Midwives (Aug. 2019).
  64. **Roblejo Balbuena H.** Summit improved genetic counseling skills; Lectured on Genetic Counseling (graduate level) at National Center of Medical Genetics in Venezuela; Updated main topics in Human Genetics; Delivered lectures in Clinical genetics to residents, counselors and other professionals; Presented on 'Genetic bases of Schizophrenia', at IX Cuban Congress of Psychiatry (Cuba, Mar. 2019); Presented on 'Prenatal Screening of Sickle Cell Disease Carriers and Inborn errors of Metabolism in Cuba', at XX Anniversary Biolab (Panama, Mar. 2019); Recipient of The National Award of the Academy of Sciences of Cuba 2018 (co-author)- 'Clinical-molecular study of Wilson's disease in Cuba'; Evaluated genetic



- cases (118) of monogenic, chromosomal or multifactorial etiology; Registered new cases (48) in the Genetic Diseases' Register of the Pediatric Hospital Center, Havana.
65. **Seven M.** Jury member for Ph.D. theses 'Evaluation of the Effectiveness of the Counseling Model Developed for Prenatal Screening and Diagnostic Tests' and 'Development of Genetic / Genomic Awareness for Pediatric Nurses Scale', Health Sciences University, Gulhane School of Nursing, Ankara, Turkey (2018, 2019); Organizing Committee member for international conference 'Nursing, Genomics & Healthcare' (UK, Apr. 2020).
  66. **Sirisena ND.** Received Korean Breast Cancer Foundation Scholarship for outstanding oral presentation on 'Pattern of Germline Genetic Variants Identified using Next-Generation Sequencing-based Testing in a Sri Lankan Cohort with Hereditary Breast Cancer', at Global Breast Cancer Conference (South Korea, Apr. 2019); Awarded Prof. N.D.W. Lionel Memorial Oration award, Sri Lankan Medical Association for research topic 'Molecular genetic determinants of sporadic breast cancer in Sri Lankan postmenopausal women' (Jul. 2019); Presented posters on 'Mouse Embryonic Stem Cell-Based Functional Analysis of Five Unclassified BRCA2 Variants Identifies One Deleterious and Four Neutral Variants' and 'Functional Studies Implicate XRCC2:rs3218550C>T as a Putative Functional Genetic Variant for Susceptibility to Sporadic Breast Cancer', at the Global Breast Cancer Conference (S. Korea, Apr. 2019); Presented poster on 'PPP1R16B is a Critical Gene in 20q11.2 Microdeletion Syndrome: Loss of Function Variant in PPP1R16B in a Girl with Multiple Congenital Anomalies', at 23<sup>rd</sup> Human Genome Meeting (S. Korea, Apr. 2019); Invited speaker at the Genomics Transforming Clinical Care Conference organized by the Board of Genetic Counseling, India (India, Jul. 2019); Planned to introduce Certificate course in Human Genetics & Genomics (2019), to improve the genomic literacy of medical health professionals; Provided diagnostic services at Human Genetics Unit, offered genetic counseling to patients (>500) with various genetic diseases and congenital birth defects, referred for appropriate supportive therapies (physiotherapy, speech therapy, occupational therapy), specialized medical management for improvement in quality of life.
  67. **Tibrewal S.** Worked closely with appointed Genetic Counselor at Dr. Shroff Charity Eye Hospital (Oct. 2018), on genetic counseling and testing for hereditary eye disorders; Organized two-day workshop in genetics at Global Eye Genetics Consortium (India, Feb. 2019), chaired by Dr. T. Iwata (National Institute of Sensory Organs, National Hospital Organization Tokyo Medical Center, Tokyo, JAPAN) and Dr. G. Prakash (NEI/NIH); Speaker on 'Genetic and Systemic Aspects of Pediatric Cataract', at Annual Conference of Delhi Ophthalmological Society (Apr. 2019); Examined, diagnosed, treated children (~7442); Counseled with help of genetic counselor patients (232) with familial hereditary eye disorders (retinoblastoma, pediatric cataract, retinal dystrophies, corneal dystrophies, keratoconus, microphthalmos, coloboma, aniridia, albinism and several others); Operated patients (26) with pediatric developmental cataracts; Rehabilitated untreatable disorders with vision devices, resulted in significant improvement in quality of life.
  68. **Uwineza A.** Lectured medical genetics and genomics in General Medicine and Graduate School (M.Med., Pathology/Pediatrics, Gynecology & Obstetrics), introduced Inborn Errors of Metabolism; Undertook training in NGS Analysis for Monogenic Disease in African Populations (Rwanda, Sept. 2018, funded by Wellcome Trust); Presented on 'Prevalence of epilepsy in Rwandan patients (Belgium, Mar. 2019); Out-patient consultations (~703) done weekly in Kigali Referral Teaching Hospital; Abnormal karyotypes found in patients (154, mostly Down Syndrome); Improved quality of life for patients with psychomotor

development delay through physiotherapy and nutrition, provided speech education for patients with learning difficulties, and psychosocial support for parents with children with genetic diseases.

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/24/2020 7:19:23 PM  
**To:** Hudgings, Carole (NIH/NIAID) [V] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=c5748df88ae14b94882fbd44ee23a953-hudgings]  
**Subject:** RE: Tin-cupping for the 2020 International Summit in Genetics and Genomics

Yes, this came to me and we've said yes.

(b)(5)

(b)(5) but of course Tony is consumed with the new coronavirus.

Hope you're well.

Hugh

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**From:** Hudgings, Carole (NIH/NIAID) [V] (b)(6)  
**Sent:** Thursday, January 23, 2020 8:04 AM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Cc:** Hudgings, Carole (NIH/NIAID) [V] (b)(6)  
**Subject:** FW: Tin-cupping for the 2020 International Summit in Genetics and Genomics  
**Importance:** High

Hi Hugh,

Tony may already have brought this to your attention. The message below says NIAID contributed \$20K last year; Martin can confirm. When this started, the rules were that NIAID supported financially, but not in other ways.

Hope all is well with you.

Best, Carole

( this is the 2<sup>nd</sup> day of snowing, 3 in a row predicted ☺ )

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**From:** Kaur, Manjit (NIH/NHGRI) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 9:58 AM  
**To:** Hudgings, Carole (NIH/NIAID) [V] (b)(6)  
**Subject:** FW: Tin-cupping for the 2020 International Summit in Genetics and Genomics  
**Importance:** High

Dear Carole,

A very Happy New Year to you and all good wishes for 2020.

We are gearing up for another Summit in 2020, and am advancing to you an email from Dr. Kastner (Scientific Dir, NHGRI) to Dr. Fauci.

AUCH0000005650

I thank you and your team for your support and guidance of our candidates in 2019, and will appreciate your support in 2020.

Will be happy to provide more information to help facilitate the process.

Thank you.

Kind Regards,

Manjit Kaur  
M.S., M.B.A.  
National Human Genome Research Institute  
National Institutes of Health  
35, Convent Drive  
Room 1B-209  
Bethesda, MD 20892  
Tel: (b)(6)  
Fax: +1 301 496 7184  
[www.genome.gov/InternationalSummit](http://www.genome.gov/InternationalSummit)

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**From:** "Kastner, Daniel (NIH/NHGRI) [E]" (b)(6)  
**Date:** Tuesday, January 21, 2020 at 9:59 PM  
**To:** "Fauci, Anthony (NIH/NIAID) [E]" (b)(6)  
**Cc:** Manjit Kaur (b)(6), "Solomon, Ben (NIH/NHGRI) [E]" (b)(6)  
**Subject:** Tin-cupping for the 2020 International Summit in Genetics and Genomics

Hi Tony,

I hope all is well with you. I'm writing in my capacity as Scientific Director of the NHGRI to thank you for your generous support of the 2019 International Summit in Genetics and Genomics. Last year we hosted 34 participants from low to middle-income countries (LMICs, as defined by the World Bank in 2019) for this month-long program. To date, we have trained 105 healthcare professionals from 43 different countries. Please see attached details, including the most recent report and last year's agenda.

In short, the purpose of this trans-NIH initiative is to advance the field of Genetics and Genomics in resource-poor countries. The Summit also helps extend the reach of the NIH to the global community.

To continue the program in 2020, I'm hoping that you will extend your previous support of \$20,000/year, and would appreciate if you would let us know if this is something that you are able and willing to do, so that we can work on documentation and logistics. In 2020 we hope to host 40 trainees. Each selected participant costs \$20,000 to cover expenses such as travel, housing, and meals. We appreciate any amount we receive from you; sponsoring at least one full participant would be ideal.

Please let us know if you have any questions or if we can help in any way. I am cc'ing Manjit Kaur, who administers the program, and Ben Solomon, the new Clinical Director of NHGRI.

With my very best wishes,

Dan

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/24/2020 7:14:18 PM  
**To:** Frankie Trull (b)(6)  
**Subject:** RE: Lunch again before too long

New coronavirus all the time.

The 6<sup>th</sup> is good. (b)(6)

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**From:** Frankie Trull (b)(6)  
**Sent:** Wednesday, January 22, 2020 7:38 PM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Subject:** Re: Lunch again before too long

Hi-  
I can make the 6th work. (b)(6)

On Jan 21, 2020, at 3:07 PM, Auchincloss, Hugh (NIH/NIAID) [E] (b)(6) wrote:

(b)(6) Did you get slammed by the Saturday storm that did almost nothing to DC but looked like it might be much worse out your way.

(b)(6) January 29, February 4 or 6 are open for me.

Hugh

Hugh Auchincloss, M.D.  
Deputy Director, NIAID  
National Institutes of Health  
Bldg. 31 (7A/03), 31 Center Drive, MSC 2520  
Bethesda, MD 20892  
Phone: (b)(6)

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/31/2020 8:20:30 PM  
**To:** Marston, Hilary (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=ab30660917b942ffba9ae95d631116f3-marstonhd]  
**CC:** Marston, Hilary (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=ab30660917b942ffba9ae95d631116f3-marstonhd]; Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cdbb7320d229399d09d-gillesm]  
**Subject:** FW: NHPRP WG Meeting minutes

Hilary, see the part about the Nonhuman Primate Research Centers jumping into action.

---

**From:** Hild, Sheri (NIH/OD) [E] (b)(6)  
**Sent:** Friday, January 31, 2020 3:17 PM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6)  
**Subject:** RE: NHPRP WG Meeting minutes

Hugh,

Thanks for the quick response and feedback (b)(5)  
(b)(5)

Happy Friday! Sheri

---

**From:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Sent:** Friday, January 31, 2020 3:00 PM  
**To:** Hild, Sheri (NIH/OD) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6)  
**Subject:** RE: NHPRP WG Meeting minutes

The minutes are comprehensive. Great work. (b)(5)  
(b)(5)

And thanks about the concept clearance materials.

Hugh

---

**From:** Hild, Sheri (NIH/OD) [E] (b)(6)  
**Sent:** Friday, January 31, 2020 2:49 PM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)

Cc: Gilles, Sharon (NIH/NIAID) [E] (b)(6)

Subject: NHPRP WG Meeting minutes

Hi Hugh,

Attached are the draft minutes for your review. I have also received some suggestions to (b)(5)

(b)(6)

Thanks much, Sheri

PS I wanted to let you know that the NPRCs are organizing to address the coronavirus outbreak. I am linked in with one of your PO's Jean Patterson. An Open Data Portal has been provided by Wisconsin NPRC and a working group is being formed. We are working toward coordinated efforts and open data sharing. ORIP is now allowing NPRC's to have expedited review of pilot projects on coronavirus to allow flexibility in supporting this research area.

Sheri Ann Hild, PhD  
Health Science Administrator  
Division of Comparative Medicine, ORIP, DPCPSI  
NIH Office of the Director  
Office: (b)(6)  
Mobile (b)(6)  
(b)(6)  
6701 Democracy Blvd., Room 956, MSC 4877  
Bethesda, MD 20892-4877

**ORIP is developing its FY 2021-2025 Strategic Plan and invites your feedback!  
Request for Information (NOT-OD-20-050) is open until February 7, 2020**

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/21/2020 6:28:58 PM  
**To:** Eiss, Robert (NIH/FIC) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=707887ee7ba548e1a0ae55f683ce2017-eissr]  
**CC:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cdbb7320d229399d09d-gillesm]  
**Subject:** RE: Wednesday subcommittee meeting

Sorry, I forgot about the World Economic Forum. By all means let's do next week. Wednesday is better for me. You can add the Wuhan coronavirus- I'll give a brief update on our plans for a response.

---

**From:** Eiss, Robert (NIH/FIC) [E] (b)(6)  
**Sent:** Tuesday, January 21, 2020 12:47 PM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6)  
**Subject:** RE: Wednesday subcommittee meeting

Hi Hugh

Are you open to rescheduling for next week – either Wednesday at the same time or Thursday? I've been focused on the World Economic Forum preparations for FC. If so, here are the topics I would propose we might cover and I can send a note out to ensure a quorum:

1. NCI- Cancer Research UK Grand Challenges - a novel funding model
2. GDPR update
3. WEF outcomes
4. HIROs agenda
5. Plans for Common Fund project in data science
6. Update on ClinRegs

---

**From:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Sent:** Tuesday, January 21, 2020 12:22 PM  
**To:** Eiss, Robert (NIH/FIC) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6)  
**Subject:** Wednesday subcommittee meeting

Rob, what do you think about tomorrow. I'm happy to have a subcommittee meeting but do we have any agenda items?

Hugh

Hugh Auchincloss, M.D.  
Deputy Director, NIAID  
National Institutes of Health  
Bldg. 31 (7A/03), 31 Center Drive, MSC 2520  
Bethesda, MD 20892  
Phone: (b)(6)

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/21/2020 8:00:40 PM  
**To:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]  
**Subject:** FW: ICRS rescheduled for January 29, 3:30 PM - 5:00 PM

**From:** Eiss, Robert (NIH/FIC) [E] (b)(6)  
**Sent:** Tuesday, January 21, 2020 2:56 PM  
**To:** Kline, Lydia (NIH/OD) [E] (b)(6); Smolskis, Mary (NIH/NIAID) [E] (b)(6); Tapley, Kate (NIH/OD) [E] (b)(6); Western, Karl (NIH/NIAID) [V] (b)(5); Millum, Joseph (NIH/CC/BEP) [E] (b)(6); Collier, Elaine (NIH/NCATS) [E] (b)(6); Engelgau, Michael (NIH/NHLBI) [V] (b)(6); Mensah, George (NIH/NHLBI) [E] (b)(6); Kutlesic, Vesna (NIH/NICHD) [E] (b)(6); Handley, Gray (NIH/NIAID) [E] (b)(6); Nightingale, Stuart (NIH/OD) [C] (b)(6); Gross, Thomas (NIH/NCI) [E] (b)(6); Berger, Adam (NIH/OD) [E] (b)(6); Rausch, Dianne (NIH/NIMH) [E] (b)(6)  
**Cc:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Harshman, Terri (NIH/NCI) [E] (b)(6); Flores Rivas, Silvia (NIH/NIAID) [E] (b)(6); Sizemore, Christine (NIH/FIC) [E] (b)(6); Grady, Christine (NIH/CC/BEP) [E] (b)(6); Harshman, Terri (NIH/NCI) [E] (b)(6); Kilmarx, Peter (NIH/FIC) [E] (b)(6); Officer, Jackie (NIH/FIC) [E] (b)(6); Nuriddin, Fajar (NIH/FIC) [C] (b)(6); Pringle, Beverly (NIH/NIMH) [E] (b)(6)  
**Subject:** ICRS rescheduled for January 29, 3:30 PM - 5:00 PM

Dear colleagues,

We are rescheduling tomorrow's ICRS meeting to next week, due to conflicting commitments. The meeting will now take place on **Wednesday, January 29, from 3:30 PM-5:00 PM**. I will confirm the conference room location in Building 31. Could you kindly confirm your availability so that we can ensure this date is viable for the group? Thanks for your flexibility

Following are planned agenda topics, and welcome additional ideas:

- *Wuhan coronavirus – plans for a response*
- *GDPR update*
- *Relevant items from World Economic Forum (Dr. Collins participating)*
- *HIROs annual meeting in March*
- *Update on the NIH Common Fund's Harnessing Data Science for Health Discovery and Innovation in Africa program*
- *NCI- Cancer Research UK Grand Challenges - a novel funding model (tentative)*
- *Update on ClinRegs (tentative)*

I am very pleased to welcome Dr. Dianne Rausch to the group. Dianne is replacing Beverly Pringle, (b)(6) I anticipate many of you know Dianne, who serves as Director of NIMH's Division of AIDS Research.

Best,

**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/22/2020 12:56:39 PM  
**To:** Marston, Hilary (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=ab30660917b942ffba9ae95d631116f3-marstonhd]  
**CC:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]; Eisinger, Robert (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=0bad2a8c45514ee48985880de66674ad-eisinger]  
**Subject:** RE: Urgent FOA

Sure, check with Mathew. (b)(5)

(b)(5)

**From:** Marston, Hilary (NIH/NIAID) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 7:52 AM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6); Eisinger, Robert (NIH/NIAID) [E] (b)(6)  
**Subject:** Fwd: Urgent FOA

Please see below. Would you like to ask asf? Also if helpful I can check with Matthew (b)(5)

Begin forwarded message:

**From:** "Cassetti, Cristina (NIH/NIAID) [E]" (b)(6)  
**Date:** January 22, 2020 at 7:45:34 AM EST  
**To:** "Marston, Hilary (NIH/NIAID) [E]" (b)(6); "Eisinger, Robert (NIH/NIAID) [E]" (b)(6)  
**Subject:** Urgent FOA

Hi Hilary and Bob,

Can you please check with Dr. Fauci to see if it's (b)(5)

(b)(5)

Cristina

Emily,

(b)(5)

(b)(5)

(b)(5)

(b)(5)

Thanks,

Alan

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/28/2020 4:11:09 PM  
**To:** Crawford, Chase (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=37f84b90ad76401e896782da76cdee86-crawfordca]; Haskins, Melinda (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=545e01141619453bb4fc1dcde6c45887-haskinsm]  
**CC:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]  
**Subject:** FW: Biocentury/@steveusdin1: At least 8 #2019-nCoV vaccines under development using a variety of technologies <http://bit.ly/2O4OhjH>

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**From:** Folkers, Greg (NIH/NIAID) [E] (b)(6)  
**Sent:** Tuesday, January 28, 2020 11:10 AM  
**To:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6)  
**Subject:** FW: Biocentury/@steveusdin1: At least 8 #2019-nCoV vaccines under development using a variety of technologies <http://bit.ly/2O4OhjH>

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**From:** Folkers, Greg (NIH/NIAID) [E] (b)(6)  
**Sent:** Monday, January 27, 2020 12:13 PM  
**Subject:** Biocentury/@steveusdin1: At least 8 #2019-nCoV vaccines under development using a variety of technologies <http://bit.ly/2O4OhjH>

At least 8 #2019-nCoV vaccines under development using a variety of technologies. List below. In addition at least three groups are working on mAbs: Regeneron, Vir, and NIH's NIAID. mAbs might be ready faster and provide both prophylaxis and treatment.

| <b>Company/group</b>  | <b>Vaccine technology</b>  |
|---|--|
| Codagenix Inc.  | computationally designed live attenuated virus   |
| CureVac AG,<br>Inovio Pharmaceuticals Inc (funded by CEPI)  | RNA vaccine<br>DNA vaccine   |
| Moderna Inc. (partnered w/NIAID, funded by CEPI)  | RNA vaccine  |
| Novavax Inc.  | Protein-based (recombinant nanoparticles)  |
| Texas Children's Hospital Center for Vaccine Development at Baylor College of Medicine; University of Texas Medical Branch, the New York Blood Center and the Virology Center at Fudan University | Protein-based [investigating repurposing a SARS candidate vaccine and/or creating a new vaccine] |
| The University of Queensland (funded by CEPI)   | Protein-based  |
| University of Saskatchewan's Vaccine and Infectious Disease Organization - International Vaccine Centre   | Protein-based  |

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