Using Genomic Information from Preconception through Early Childhood: A Workshop

Committee

Natasha Bonhomme

Co-Chair

Natasha F. Bonhomme is Founder of Expecting Health, an organization dedicated to advancing patient and family education, engagement, and navigation across newborn screening, genetics, and maternal and child health. Her work focuses on translating advances in genomics into equitable, patient-centered clinical care through stakeholder engagement, implementation strategies, health communication, and systems change. Bonhomme created and oversees Baby's First Test, a national newborn screening resource for families and health care professionals and developed the Navigate Newborn Screening (NavigateNBS) program, which has helped thousands of families understand screening results, connect with specialists and support organizations, and navigate follow-up care. Bonhomme previously served as an organizational representative to the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children and currently co-chairs the BRIDGES-NBS Community Advisory Board, helping guide patient and community engagement across multiple genomic newborn screening research sites. She has testified before the U.S. Senate on newborn screening policy and serves on national advisory committees focused on genomics, maternal and child health, and patient engagement.

Aaron Goldenberg

Co-Chair

Aaron Goldenberg, PhD, MPH, is Professor and Vice Chair in the Department of Bioethics at Case Western Reserve University (CWRU) and Director of the CWRU Bioethics Center for Health and Genomics. Goldenberg's expertise spans bioethics, health behavior and health education, public health ethics, public health genetics, and qualitative and quantitative research design and analysis. His research focuses on the ethical, legal, and social issues associated with research and clinical care for rare diseases and the integration of new genomic technologies into research, clinical, and public health settings. He has a particular interest in incorporating family perspectives into the ethical and social implications of expanded genetic and genomic screening in newborns and children, including how genetic information may influence care decisions and the diagnostic and intervention experiences of families. He is also a nationally recognized expert in newborn screening, rare disease treatment, including the development of gene-targeted therapies, and pediatric ethics. Goldenberg serves as co-chair of the Ethics, Legal & Social Workgroup of the Association of Public Health Laboratories. He earned a PhD and MA in Bioethics from Case Western Reserve University and an MPH from the University of Michigan. He previously served on the National Academies planning committees for the workshops Exploring the Current Landscape of Consumer Genomics and Next-Generation Newborn Screening: The Promise and Perils of DNA Sequencing of Newborns at Birth.

Marilyn Hammer

Member

Marilyn Hammer, PhD, DC, RN, FAAN, is Professor in the School of Nursing at Northeastern University's Bouvé College of Health Sciences and Director of the Phyllis F. Cantor Center for Research in Nursing and Patient Care Services at Dana-Farber Cancer Institute. Previously, she served on the faculty of the New York University Rory Meyers College of Nursing and as Director of Research and Evidence Based Practice at Mount Sinai Hospital in New York City. Hammer's research focuses on precision health symptom science, with the goal of understanding interindividual variability in symptom experiences and identifying omics and biological mechanisms associated with adverse symptom profiles among individuals with cancer and other chronic conditions. Building on earlier research investigating associations between glycemic status and immune function in patients with cancer, her work seeks to advance precision health approaches to symptom management. Hammer is a Fellow of the American Academy of Nursing, the New York Academy of Medicine, and the Royal Society of Medicine. She earned a PhD in Nursing Science/Oncology and an MN in Clinical Nurse Specialist/Oncology from the University of Washington, a BSN from the University of Texas at Arlington, a Doctor of Chiropractic degree from Life Chiropractic College West, and a BS in Business Marketing from Long Island University/C.W. Post College.

Mira Irons

Member

Mira Irons, MD, is Associate Chief of the Division of Genetics and Genomics at Boston Children's Hospital, where she leads the division's clinical and educational activities. She also serves as Program Director for the Harvard Medical School Genetics Training Program and is a faculty member at Harvard Medical School. Previously, she served as Chief Health and Science Officer at the American Medical Association. Irons is a medical geneticist and pediatrician whose professional activities focus on clinical care and innovation, education, and advocacy. Her work emphasizes advancing the responsible integration of genetics and genomics into health care, educating health professionals and the public, and promoting equitable access to genetic services. She is board certified in Clinical Genetics, Clinical Biochemical Genetics, and Pediatrics. Irons is President of the American College of Medical Genetics and Genomics (ACMG). She has held numerous leadership roles in national genetics organizations, including CME Officer, Chair of the Education Committee, and member of the Board of Directors of ACMG and the ACMG Foundation; Council Member and President of the Association of Professors of Human and Medical Genetics; and member of the Advocacy Committee of the American Society of Human Genetics. She earned her medical degree from Northwestern University Feinberg School of Medicine and completed her pediatric residency and genetics fellowships at Massachusetts General Hospital and Boston Children's Hospital.

Debra G. Leonard

Member

Debra G. B. Leonard, MD, PhD, is Professor Emerita and former Chair of Pathology and Laboratory Medicine at the Robert Larner, M.D. College of Medicine at the University of Vermont and the University of Vermont Health Network. Previously, she served as Vice Chair for Laboratory Medicine at Weill Cornell College of Medicine and Director of the Molecular Pathology Laboratory at the University of Pennsylvania. Leonard is a pathologist with expertise in molecular pathology and molecular genetic pathology. Her professional interests include pathology, laboratory medicine, and molecular diagnostics. She is board certified in Anatomic Pathology and Molecular Genetic Pathology. Leonard is the recipient of the Sister Elizabeth Candon Award for Distinguished Service, the Larner College of Medicine Polaris Gender Equity Award for Outstanding Mentorship, the Association for Molecular Pathology Leadership Award, and the College of American Pathologists Lifetime Achievement Award. She completed Medical Scientist Training Program (MSTP) training at New York University, where she also completed her Anatomic Pathology residency, Surgical Pathology fellowship, and postdoctoral research fellowship. Leonard served on the National Academies Roundtable on Genomics and Precision Health from 2007–2018 and again in 2020 and 2024. She also served on the Secretary's Advisory Committee on Genetics, Health and Society from 2003–2006.

Robert L. Nussbaum

Member

Robert Nussbaum, MD, is a medical geneticist and physician-scientist with longstanding expertise in genomic medicine, molecular diagnostics, and the clinical implementation of genetic testing. He previously served as Chief Medical Officer of Invitae, Chief of the Division of Genomic Medicine at UCSF Health, and Chief of the Genetic Disease Research Branch at the National Human Genome Research Institute at the National Institutes of Health. Nussbaum's work has focused on advancing the responsible use of genomics in patient care across cancer, cardiovascular disease, and inherited disorders. He is widely recognized for his contributions to neurogenetics, including co-identifying the first genetic cause of inherited Parkinson's disease. He has authored or co-authored numerous peer-reviewed publications and is a co-author of the textbook Genetics in Medicine. Nussbaum is an elected member of the National Academy of Medicine and the American Academy of Arts and Sciences. He serves as co-chair of the National Academies Roundtable on Genomics and Precision Health and in advisory roles across the genomics and diagnostics landscape. He earned his MD from Harvard Medical School and completed a fellowship in Medical Genetics at Baylor College of Medicine.

Kanwaljit Singh

Member

Kanwaljit Singh, MD, MPH, MBA, is Executive Director of the International Neonatal Consortium and Director of Pediatric Programs at Critical Path Institute, where he leads international public-private collaborations to advance neonatal and pediatric therapeutic development through regulatory science, real-world evidence, and data-driven innovation. He works with regulatory agencies, industry, academic investigators, and patient advocacy organizations to develop frameworks for evidence generation in neonatal and pediatric populations. Singh's work focuses on the integration of longitudinal clinical and genomic data, quantitative epidemiology, safety science, and advanced analytic methods to improve therapeutic development and evaluation across the maternal-fetal-neonatal continuum. His research interests include precision medicine, risk stratification, biomarker development, and longitudinal evidence generation in pediatric populations. He has led multiple FDA-funded initiatives to harmonize neonatal electronic health record data, develop real-world data infrastructure, and create consensus-based safety and outcome assessment tools. Singh received his MBBS from Government Medical College and Hospital, Panjab University, Chandigarh, India; an MPH in Quantitative Methods from Harvard University; and an Executive MBA from the University of California, Los Angeles.

Sindhu Srinivas

Member

Sindhu Srinivas, MD, MSCE, is Professor of Obstetrics and Gynecology, Executive Director of the Hospital of the University of Pennsylvania–Cedar Avenue, and Associate Chief Medical Officer for Quality and Safety for the Hospital of the University of Pennsylvania. She is an obstetrician-gynecologist and maternal-fetal medicine specialist. Srinivas leads a nationally recognized research program spanning clinical and epidemiologic studies, health services research, and care delivery science. Her work examines how innovative models of care and the organization of health systems influence maternal outcomes across prenatal, intrapartum, and postpartum settings, with a sustained focus on advancing equity. For more than 15 years, her research has explored racial and ethnic differences in maternal care and outcomes. She co-developed the Heart Safe Motherhood program to improve postpartum follow-up for patients with preeclampsia and has published extensively in leading peer-reviewed journals. Srinivas recently completed her term as President of the Society for Maternal-Fetal Medicine and has served on the Philadelphia and Pennsylvania Maternal Mortality Review Committees. She earned her MD from Jefferson Medical College and her Master of Science in Clinical Epidemiology from the University of Pennsylvania.

David L. Veenstra

Member

David Veenstra, PharmD, PhD, is Professor in the Comparative Health Outcomes, Policy & Economics (CHOICE) Institute in the Department of Pharmacy at the University of Washington. His research focuses on the clinical, economic, and policy implications of precision medicine, including the cost-effectiveness of population-level genomic screening and evidence thresholds and stakeholder preferences for precision medicine. Veenstra's research has been supported by the National Human Genome Research Institute, the Centers for Disease Control and Prevention, and the National Cancer Institute. He has also worked extensively with the Academy of Managed Care Pharmacy and the Institute for Clinical and Economic Review to advance the application of cost-effectiveness analysis in managed care decision-making. Veenstra has served as a consultant for Illumina. He teaches courses in health economics and managed care and has authored five book chapters and 260 peer-reviewed publications. Veenstra earned both his PharmD and PhD in Pharmaceutical Chemistry from the University of California, San Francisco.

Neeta Vora

Member

Neeta Vora, MD, is Professor of Obstetrics and Gynecology and Director of Reproductive Genetics at the University of North Carolina at Chapel Hill. She is board certified in Obstetrics and Gynecology, Maternal-Fetal Medicine, and Clinical Genetics. Vora's research focuses on prenatal genetics and genomic medicine. She is principal investigator of a National Institute of Child Health and Human Development (NICHD)-funded R01 studying novel genes critical to human brain development using functional modeling in zebrafish. She has also served as co-investigator on multicenter studies of prenatal whole genome sequencing and patient preparation for a prenatal diagnosis of a genetic condition. She has authored more than 110 publications on prenatal genetics, including topics ranging from cell-free DNA to whole exome and whole genome sequencing. Vora earned her MD from the University of Toledo College of Medicine. She completed residencies in Obstetrics and Gynecology and Medical Genetics and Genomics, as well as a fellowship in Maternal-Fetal Medicine, at Tufts Medical Center.

Catherine A. Wicklund

Member

Cathy Wicklund, MS, CGC, is Clinical Strategy Lead for Family Health in Medical Affairs at Myriad Genetics, where she leads a team focused on research, clinical strategy, and thought leader engagement to advance equitable access to genetic testing. Previously, she served as Director of the Graduate Program in Genetic Counseling at Northwestern University and provided prenatal genetic counseling services in the Department of Obstetrics and Gynecology. Earlier in her career, she directed Prenatal Genetic Counseling Services and co-directed the Graduate Program in Genetic Counseling at the University of Texas Medical School. Wicklund's research interests include reproductive genetics, genomics and precision health, implementation science, health inequities, and education. She has published on reproductive genetics, education, newborn screening, reproductive rights, and precision health. Wicklund is a former President of the National Society of Genetic Counselors and has held numerous leadership roles within the American Society of Human Genetics. She serves as the National Society of Genetic Counselors representative and co-chair of the National Academies Roundtable on Genomics and Precision Health and serves on advisory committees focused on graduate education, workforce development, equitable access to genomic services, and newborn and early childhood screening. She earned a Master of Science in Genetic Counseling from the University of Texas Graduate School of Biomedical Sciences at Houston and became board certified by the American Board of Genetic Counseling in 1996.