

Board on Health Sciences Policy

Committee

Sharon Terry

Chair

Sharon F. Terry, M.A. (Chair), is President and CEO of Genetic Alliance, an enterprise engaging individuals, families and communities to transform health. Genetic Alliance works to provide programs, products and tools for ordinary people to take charge of their health and to further biomedical research.

As 'just a Mom' with a master's degree in theology, she cofounded PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE), in response to the diagnosis of PXE in her two children in 1994. She is a co-discoverer of the ABCC6 gene, and patented it to ensure ethical stewardship in 2000, assigning her rights to the foundation. She subsequently developed a diagnostic test and conducts clinical trials. She is the author of 150 peer-reviewed papers, of which 30 are clinical PXE studies. Her story is the topic of her TED Talk and TED Radio Hour.

In her focus at the forefront of consumer participation in genetic research, services and policy, she serves in a leadership role on many of the major international and national organizations, including the Precision Medicine Initiative Cohort Advisory Panel; Accelerating Medicines Partnership; the National Academy of Medicine Roundtable on Genomics and Precision Health; the PhenX scientific advisory board; the Global Alliance for Genomics and Health; the International Rare Disease Research Consortium Executive Committee; Genome Medical; LunaDNA; and as Founding President of EspeRare Foundation of Geneva, Switzerland. Terry is the founder of the Genetic Alliance Registry and Biobank. She is on the editorial boards of several journals, including Genome, Patient Engagement Editor for Genetic Alliance's official journal Genetic Testing and Molecular Biomarkers, and Chief Patient Advisor for Clinical and Translational Science. She led the coalition that was instrumental in the passage of the Genetic Information Nondiscrimination Act. She received an honorary doctorate from Iona College for her community engagement work in 2006; the 2011 Research!America Distinguished Organization Advocacy Award and an inaugural member of Disruptive Women in Health Care in 2009; and the Clinical Research Forum and Foundation's Annual Award for Leadership in Public Advocacy in 2011. She was named one of FDA's "30 Heroes for the Thirtieth Anniversary of the Orphan Drug Act" in 2013. She is co-inventor of the Program for Engaging Everyone Responsibly (PEER), receiving a large grant from the Robert Wood Johnson Foundation in 2014. She was Co-PI of the PCORnet Coordinating Center and Chair of the PCORnet Engagement Committee. She was a member of the Blue Ribbon Panel's Working Group on Enhanced Data Sharing for the Cancer Moonshot. She was named a National Associate of the National Research Council, National Academies of Engineering, Sciences, and Medicine for her extraordinary service. She received the Health 2.0 Health Activist award in 2016. In 2019, she won the Luminary Award from the Precision Medicine World Conference. She received the American Society of Human Genetics Advocacy Award in 2021.

Terry is an Ashoka Fellow. She is an avid student and teacher of Gestalt Awareness Practice, offering workshops and individual facilitation. Her daughter and son are why she started down this path. They, their wives, and her granddaughter ground, gladden, and enliven her.

Elisabeth Belmont

Member

Elisabeth Belmont, Esq. serves as Corporate Counsel for MaineHealth which is ranked among the nation's top 100 integrated healthcare delivery networks and has combined annual revenues of nearly \$2 billion. She is responsible for a myriad of complex issues faced by an integrated delivery system on a daily basis and has a specialty concentration in emerging technologies and healthcare innovation. Ms. Belmont has participated in a number of national initiatives where quality improvement, patient safety and information technologies intersect including events sponsored by the DHHS Office of the National Coordinator, DHHS Office of the Inspector General, American Health Lawyers Association, American Society of Healthcare Risk Management and American Association for the Advancement of Science. She serves as a member of the Division Committee of the Health and Medicine Division and the Board on Health Sciences Policy of the National Academies of Sciences, Engineering, and Medicine. She is a former member of the National Academies' Board on Health Care Services of the Health and Medicine Division, and participated as a member of the National Academies' Consensus Study Committees on Improving Diagnosis in Health Care and Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being. Additionally, Ms. Belmont is a Past President of the American Health Lawyers Association, former Chair and co-founder of the Association's Health Information & Technology Practice Group and founding editor of HIT News, and former Chair of the Association's Quality in Action Task Force. She also was appointed co-Chair of the National Quality Forum's Health IT Patient Safety Measures Standing Committee. Ms. Belmont previously served on the Advisory Boards of Bloomberg's Health Law Reporter and Health Law & Business News. Ms. Belmont co-authored agency guidance, EHR Contracts Untangled: Selecting Wisely, Negotiating Terms and Understanding the Fine Print, for the DHHS Office of the National Coordinator. She is a nationally recognized lecturer and author on a myriad of health law topics. Ms. Belmont is the recipient of numerous honors including being named by Modern Healthcare as one of the 2007 Top 25 Most Powerful Women in Healthcare, being selected to receive the American Health Lawyers Association 2014 David J. Greenburg Service Award, and being named by the National Academies of Sciences, Engineering, and Medicine as a 2016 National Associate.

Richard A. Berman

Member

Richard Berman is the Associate Vice President for Strategic Initiatives for Innovation and Research at the University of South Florida, visiting social entrepreneurship professor in the Muma College of Business, and a professor in the institute for Advanced Discovery & Innovation. He is currently an elected member of the National Academy of Medicine of the National Academy of Sciences (formerly known as the Institute of Medicine) in Washington, DC, and is a board member of EmblemHealth.

He is also a board member for the Savannah Centre for Diplomacy, Democracy and Development in Abuja, Nigeria, and the American International Health Alliance (AIHA). He served as a Fulbright Specialist in both Uganda and Rwanda. He also served as the Special Advisor to the leader of the African Union-United Nations Peace Keeping Mission in Darfur. Also, an expert advisor to the European Unions-Joint Research Centre. Additionally, he serves on the NASDAQ listed board of ONTRAK.

He previously served on the board of directors for the Lillian Vernon Corporation. Previously, Richard has worked as a management consultant for McKinsey & Company, the Executive Vice President of NYU Medical Center and Professor of Health Care Management at the NYU School of Medicine. He has also held various roles at Korn Ferry International, Howe-Lewis International, served in 2 cabinet positions in New York State Government, and the US Department of Health Education and Welfare. In 1995, Mr. Berman was selected by Manhattanville College to serve as its tenth President. Mr. Berman is credited with the turnaround of the College, where he served until 2009.

Mr. Berman received his BBA, MBA, and MPH from the University of Michigan and holds honorary doctorates from Manhattanville College and New York Medical College.

In his spare time, he enjoys playing tennis, golf and being the absolute best PopPop he can be to all 7 of his grandkids!

Amander Clark

Member

Amander Clark, PhD is Professor of Molecular Cell and Developmental Biology and Director of the UCLA Center for Reproductive Science, Health and Education at the University of California Los Angeles. Dr. Clark is a stem cell scientist, geneticist and developmental biologist who is internationally recognized for her work on pluripotent stem cells and building models of the ovary, germline and embryo. Professor Clark has authored over one hundred research articles, and is regularly invited to speak on the use of stem cells to understand fertility, infertility and women's health concerns. Professor Clark's research is supported by grants from the National Institute of Health, the Bill and Melinda Gates Foundation, the California Institute of Regenerative Medicine, the Templeton Foundation and the LucaBella Foundation. Professor Clark's work has been recognized by Awards from the International Society for Stem Cell Research, STOP Cancer, the Lance Armstrong Foundation, and the Concern Foundation as well as lectureships from national and international scientific and medical societies. In 2022 she was awarded the Founders Medal from the Australian and New Zealand Society for Reproductive Biology. Professor Clark is currently the inaugural Director of the UCLA Center for Reproductive Science, Health and Education, and President of the International Society for Stem Cell Research, a global non-profit that promotes excellence in stem cell science and applications to human health.

Steven K. Galson

Member

Steven K. Galson, M.D, M.P.H., retired from Amgen in July after almost 12 years in senior roles in Research & Development including senior vice president, Global Regulatory Affairs and Safety. He joined Amgen in 2010 as vice president, Global Regulatory Affairs. Prior to Amgen, Galson was senior vice president for Civilian Health Operations and chief health scientist at Science Applications International Corporation. Galson spent more than 20 years in government service, including two years as acting Surgeon General of the United States. Previously, he served as director of the Food and Drug Administration's (FDA) Center for Drug Evaluation and Research (CDER), where he provided leadership for the center's broad national and international programs in pharmaceutical regulation. Galson began his Public Health Service (PHS) career as an epidemiological investigator at the Centers for Disease Control and Prevention (CDC) after completing a residency in internal medicine at the Hospitals of the Medical College of Pennsylvania. He also held senior-level positions at the Environmental Protection Agency (EPA); the Department of Energy, where he was chief medical officer; and the Department of Health and Human Services. Prior to his arrival at the FDA, Galson was director of the EPA's Office of Science Coordination and Policy, Office of Prevention, Pesticides and Toxic Substances. Galson holds a B.S. from Stony Brook University, an M.D. from Mt. Sinai School of Medicine, and an M.P.H. from the Harvard School of Public Health. In 2008, Galson received an Honorary Doctor of Public Service Degree from Drexel University School of Public Health, and in 2015, he received the Jacobi Medallion Award from Icahn Mount Sinai School of Medicine. In 2018 Galson was named the Health Leader of the Year from the Commissioned Officers Association of the United States Public Health Service. Galson is a member of the Clinical Trials Transformation Initiative Executive Committee, and on the board of trustees for the Keck Graduate Institute in Claremont, CA. He is also a member of the Board of Directors of Biocryst Pharmaceuticals and Elephas Biosciences.

Garth N. Graham

Member

A cardiologist, researcher and public health expert, Garth is the Director and Global Head of Healthcare and Public Health at Google Health/YouTube. He previously served in two US administrations as US Deputy Assistant Secretary for Health, and was Assistant Dean for Health Policy and Chief of Health Services Research in the Department of Medicine at the University of Florida School of Medicine. He also served as President of the Aetna Foundation as well as Vice President & Chief Community Health Officer at CVS Health. He currently sits on several boards, including the Advisory Council to the Director of the NIH, the National Academy of Sciences, Engineering, and Medicine's Board on Health Sciences Policy, and the board of the National Quality Forum. He previously served on the National Heart, Lung and Blood Institute Advisory Council.

An elected member of the National Academy of Medicine, Garth obtained his MD at Yale University School of Medicine, MPH at Yale School of Public Health, Internal Medicine at Massachusetts General Hospital and Cardiology fellowship at Johns Hopkins. He holds three board certifications including internal medicine, cardiology and interventional cardiology. He also holds an honorary doctorate of laws from Regis College and an honorary degree from the Eastern Virginia Medical School in 2021.

M. Ehsan Hoque

Member

Ehsan Hoque, Ph.D., is an Associate Professor of Computer Science at the University of Rochester, where he also co-directs the Rochester Human-Computer Interaction (ROC HCI) Lab. His research focuses on leveraging artificial intelligence techniques to enhance human capabilities. By utilizing machine learning to model and analyze human behavior and relationships, Dr. Hoque designs interactive systems that foster equity and accessibility in health care. His work has significantly improved the lives of those facing socio-emotional communication challenges, such as individuals with autism, severe anxiety, neurodegenerative diseases, PTSD, aging, and terminal illnesses. Dr. Hoque obtained his Ph.D. from the Massachusetts Institute of Technology in 2013, with his dissertation on "Computers to help with conversations" being featured as one of MIT's most unconventional inventions by the MIT Museum.

His innovative health intervention contributions have earned him numerous accolades, including the MIT Technology Review Top Innovators Under 35 Award in 2016. In 2017, he was named one of ten early- to mid-career scientists to watch by Science News, and in 2018, he received US Army Young Investigator Award and NSF CAREER award. In 2020, the National Academy of Medicine recognized him as one of the emerging leaders in health and medicine. Dr. Hoque is a Distinguished Member of the Association of Computing Machinery (ACM), the world's largest computing society, and a Senior Member of the Association for the Advancement of Artificial Intelligence (AAAI), the largest scientific society for AI.

In his personal life, Dr. Hoque is an enthusiastic triathlete who is currently preparing to complete IRONMAN Lake Placid in July 2023.

Phuong Khanh Morrow

Member

P.K. Morrow is the Head of the Oncology Therapeutic Area Unit at Takeda Pharmaceuticals, where she has responsibility for the oncology R&D strategy, development portfolio goals and budget.

Prior to joining Takeda, P.K. served as Chief Medical Officer at CRISPR Therapeutics, where she was responsible for end-to-end development of clinical programs spanning hematology, oncology, diabetes and cardiovascular diseases. In partnership with Vertex Pharmaceuticals, she helped lead the development of exa-cel, the first CRISPR gene-editing therapy to be approved by the FDA for the treatment of severe sickle cell disease and transfusion-dependent beta-thalassemia.

Prior to CRISPR Therapeutics, P.K. spent over a decade at Amgen, where she served as Vice President and Global Therapeutic Area Head of Hematology, GI Oncology, GU Oncology, and Bone Diseases. Before joining industry, she was on the faculty of MD Anderson Cancer Center (MDACC).

P.K. received an M.D. from the University of Texas Medical School. She completed her internal medicine residency at Baylor College of Medicine and a Hematology/Oncology Fellowship at MDACC, during which she received the Clifton D. Howe Award for Clinical Excellence, the ASCO Young Investigator Award for her translational work in head and neck cancer, and served as the Lyndon Baines Johnson Chief Fellow.

Charmaine D. Royal

Member

Charmaine Royal is the Robert O. Keohane Professor of African & African American Studies, Biology, Global Health, and Family Medicine & Community Health at Duke University. She directs the Duke Center on Genomics, Race, Identity, Difference and the Duke Center for Truth, Racial Healing & Transformation. She held previous faculty appointments at Howard University.

Dr. Royal's research, scholarship, and teaching focus on ethical, social, scientific, and clinical implications of human genetics and genomics, with an emphasis on issues at the intersection of genetics and race. She has chaired, co-chaired, or served on numerous national and international advisory boards and committees, including three National Academies' committees, the most recent of which is the committee that produced 'Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field'.

Dr. Royal obtained a bachelor's degree in microbiology, master's degree in genetic counseling, and doctorate in human genetics from Howard University. She completed postgraduate training in ethical, legal, and social implications (ELSI) research and bioethics at the National Human Genome Research Institute of the National Institutes of Health, and in epidemiology and behavioral medicine at Howard University Cancer Center.

Matthew K. Wynia

Member

Matthew Wynia, M.D., M.P.H., Dr. Wynia is Board certified in Internal Medicine and Infectious Diseases, with additional training in public health and health services research. He led the Institute for Ethics at the American Medical Association for 15 years and founded its Center for Patient Safety before moving in 2015 to become the Director of the University of Colorado's Center for Bioethics and Humanities (CBH). The CBH is involved in the education for every health professions student at CU, facilitates clinical ethics case consultation for hospitals on the Anschutz Medical Campus, and carries out a research agenda to better understand the complex ethical challenges facing medicine and society. The Center also runs the annual Aspen Ethical Leadership Program and several major community engagement programs, including the annual Holocaust Genocide Contemporary Bioethics program and the Hard Call® podcast series.

Dr. Wynia has led national projects on issues including public health and disaster ethics; ethics and quality improvement; communication, team-based care and engaging patients as members of the team; and medicine and the Holocaust. He has delivered more than 2 dozen named lectures and visiting professorships and is the author of more than 160 published articles, co-editor of several books, and co-author of a book on fairness in health care benefit design. He is a Fellow of the Hastings Center, past president of the American Society for Bioethics and Humanities (ASBH), and past-chair of the Ethics Forum of the American Public Health Association (APHA) and the Ethics Committee of the Society for General Internal Medicine (SGIM).

David Blazes

Member-at-Large

David Blazes, M.D., M.P.H., joined the Surveillance and Epidemiology program at the Bill and Melinda Gates Foundation in May 2016 after serving as a physician epidemiologist in the Navy. Currently, he leads the Genomics, Epidemiology & Modeling initiative on the Enterics, Diagnostics, Genomics, and Epidemiology team. In his 21-year Navy career, he served as Director of Infectious Diseases Research at Bethesda Naval Hospital, Department Head of Infectious Diseases on the hospital ship USNS COMFORT, and Director of the Emerging Infections Department at the Naval Medical Research Unit Six in Peru. His work there involved developing disease surveillance systems in resource-limited settings, working with local officials in responding to outbreaks, and characterizing several novel pathogens. After returning to Washington, DC, he directed the Department of Defense's global disease surveillance efforts and contributed to the Department's global health security work. He served as the chief advisor to the Navy Surgeon General on Infectious Diseases as well as on several National Security Staff/interagency working groups dealing with global health security and health diplomacy. His academic work has appeared in *Science*, *Nature* and the *LancetID*, and he recently edited a textbook on technological innovations in disease surveillance. He has previously served on the Institute of Medicine's Forum on Microbial Threats, the Infectious Disease Society of America's Global Public Health Committee/Pandemic Influenza Task Force and currently serves on the National Academy of Science's Board on Health Science Policy. Blazes graduated from the U.S. Naval Academy, did his medical training at Johns Hopkins University, and serves as an Adjunct Professor at the Uniformed Services University.

Frances E. Jensen

Member-at-Large

Frances E. Jensen, M.D. is Professor of Neurology and Chair of Neurology at the Perelman School of Medicine, University of Pennsylvania, and Co-Director of Penn Translational Neuroscience Center. She was formerly Professor of Neurology, Harvard Medical School, Director of Translational Neuroscience and senior neurologist at the Brigham and Women's Hospital and Boston Children's Hospital. After receiving her AB from Smith College and MD from Cornell Medical College, she obtained her neurology residency training at the Harvard Longwood Neurology Residency Program. Her research focuses on mechanisms of epilepsy, and the interaction of epilepsy with other disorders such as autism and dementia, to elucidate new therapies for clinical trials development. She has authored over 150 manuscripts on subjects related to her research and has been continuously funded by NIH since 1987 and was the recipient of a NIH Director's Pioneer Award in 2007 and a NIH-NINDS Javits Award in 2020. Dr. Jensen was elected as a member of the National Academy of Medicine in 2015 and the recipient of the Smith College Medal in 2020. Dr. Jensen has trained numerous clinical and basic research fellows who now hold independent faculty positions nationally and internationally. Dr. Jensen served as President of the American Neurological Association (2021-2023) and President of the American Epilepsy Society in 2012. She has served on multiple leadership boards including Society for Neuroscience and NIH. Dr. Jensen is a Trustee of the Franklin Institute in Philadelphia and is involved in community outreach for brain research and education. In addition, Dr. Jensen is an advocate for awareness of the adolescent brain development, its unique strengths and vulnerabilities, as well as their impact on medical, social, and educational issues unique to teenagers and young adults, and author of the book "The Teenage Brain", released by Harper Collins in 2015/16, translated and published in over 25 languages worldwide.

Suzet M. McKinney

Member-at-Large

Suzet M. McKinney, Dr.P.H., M.P.H., is a public health expert, medical executive, thought leader, strategic thinker and nationally recognized expert in emergency preparedness and response. As Principal and Director of Life Sciences for Sterling Bay, Dr. McKinney oversees relationships with the scientific, academic, corporate, tech, and governmental sectors involved in the life sciences ecosystem. She also leads the strategy to expand Sterling Bay's footprint in life sciences nationwide. She previously served as CEO and Executive Director of the Illinois Medical District, where she managed a 24/7/365 environment that included 560 acres of medical research facilities, labs, a biotech business incubator, universities, raw land development areas, four hospitals and more than 40 healthcare-related facilities. Within two years of leadership, Dr. McKinney accomplished a financial turnaround of the IMD, successfully retiring more than \$40 million in debt. In 2020, Dr. McKinney was appointed by Illinois Governor JB Pritzker as Operations Lead for the State of Illinois' Alternate Care Facilities, a network of alternate medical locations designed to decompress the hospital system during the COVID-19 pandemic. She worked with the U.S. Army Corps of Engineers and multiple construction, architecture and project management teams to prepare five facilities to open for overflow patient care. Dr. McKinney is also an experienced on-camera expert who has frequently discussed healthcare disparities and racial inequities amplified by the pandemic, climate-related emergencies, biological and chemical threats and natural disasters. She's been featured on CNN, ABC, NBC Nightly News, The Wall Street Journal, Forbes, Crain's Chicago Businesses and The Chicago Tribune. Prior to leading the IMD, Dr. McKinney served as the Deputy Commissioner of the Bureau of Public Health Preparedness and Emergency Response at the Chicago Department of Public Health (CDPH), where she oversaw the emergency preparedness efforts for the Department and coordinated those efforts within the larger spectrum of the City of Chicago's Public Safety activities, in addition to overseeing the Department's Division of Women and Children's Health. She also provided support to the U.S. Department of Defense's Defense Threat Reduction Agency, lending subject matter expertise in biological terrorism preparedness to the country of Poland. Previously, she served as the Sr. Advisor for Public Health and Preparedness at the Tauri Group, where she provided strategic and analytical consulting services to the U.S. Department of Homeland Security's (DHS), BioWatch Program. Her work at DHS included providing creative, responsive and operationally based problem-solving for public health, emergency management and homeland security issues, specifically chemical and biological early detection systems and the implementation of those systems at the state and local levels.