

Human Genome Editing: Scientific, Medical and Ethical Considerations

Committee

R. A. Charo

Co-Chair

R. Alta Charo, J.D., is the Warren P. Knowles Professor of Law and Bioethics at the University of Wisconsin at Madison (UW), where she is on the faculty of the Law School and the Department of Medical History and Bioethics of the medical school. Professor Charo received her B.A. biology from Harvard in 1979 and her J.D. from Columbia in 1982. She is an elected member of the World Technology Network (2004) and the Wisconsin Academy of Sciences, Arts and Letters (2005). In 2006 she was elected to membership in the National Academy of Medicine. Professor Charo served on President Obama's transition team, focusing her attention particularly on transition issues related to the National Institutes of Health (NIH), the Food and Drug Administration (FDA), bioethics, stem cell policy, and women's reproductive health. She was on leave from 2009 to 2011 to serve as a senior policy advisor on emerging technology issues in the Office of the Commissioner at FDA. In addition to teaching courses on public health law, bioethics, biotechnology law, food and drug law, reproductive rights, torts, and legislative drafting, Professor Charo has served on the UW Hospital clinical ethics committee, the UW institutional review board, and the UW bioethics advisory committee. Her federal advisory committee service includes the 1994 NIH Human Embryo Research Panel and President Clinton's National Bioethics Advisory Commission (1996 to 2001). From 2001 to 2008 she was a member of the National Academies' Board on Life Sciences and from 2006 to 2012 she was a member of the Board on Population Health and Public Health Practice.

Richard O. Hynes

Co-Chair

Richard O. Hynes, Ph.D., is Daniel K. Ludwig Professor for Cancer Research at the Massachusetts Institute of Technology (MIT). He received his B.A. in biochemistry from the University of Cambridge, U.K., and his Ph.D. in biology from MIT in 1971. After postdoctoral work at the Imperial Cancer Research Fund in London, where he initiated his work on cell adhesion, he returned to MIT as a faculty member. Dr. Hynes is a fellow of the Royal Society of London, the American Academy of Arts and Sciences, and the American Association for the Advancement of Science, and is a member of the National Academy of Sciences and the National Academy of Medicine. He has received the Gairdner Foundation International Award for achievement in medical science and the Pasarow Award for Cardiovascular Research. He was previously Associate Head and then Head of the Biology Department and served for 10 years as Director of the MIT Center for Cancer Research. He is currently a Governor of the Wellcome Trust U.K.

David W. Beier

Member

David W. Beier, J.D., is a Managing Director of Bay City Capital and has been with the firm since 2013. He is a globally recognized leader in health care policy, pricing, intellectual property, government affairs, regulatory affairs, health care economics, and product commercialization. In addition, having spent two decades as part of the senior management teams for Amgen and Genentech, the two largest biotechnology companies in the world, he contributes invaluable perspective regarding strategy for entrepreneurial biotechs, the needs of potential acquirers, and the global health care industry in general. Mr. Beier served in the White House as the Chief Domestic Policy Advisor to Vice President Al Gore during the Clinton Administration. He has served as an appointee of President Clinton on his Advisory Committee for Trade Policy and Negotiations, on the Institute of Medicine panel on the Future of Health and Human Services, and as an advisor to the President's Council of Advisors on Science and Technology. Mr. Beier was also formerly a partner in international law firm Hogan and Hartson and was formerly Counsel to the US House of Representatives Committee on the Judiciary. He has testified before Congress and the Federal Trade Commission, has written numerous law review articles and technical legal works, is regularly invited to author expert OpEds on health care, and has contributed to books on topics ranging from intellectual property, trade, privacy and justice issues. He currently serves as an appointee of Governor Brown on the California State Government Organization and the Economy Commission, as a Fellow of the Center for Global Enterprise, and teaches as an Adjunct Lecturer at the Haas School of Business at UC Berkeley. Mr. Beier received his J.D. from Albany Law School at Union University and his undergraduate degree and Colgate University. He is admitted to practice law in New York and the District of Columbia.

Juan Carlos I. Belmonte

Member

Juan Carlos Izpisua Belmonte, Ph.D., is a professor in the Gene Expression Laboratories at the Salk Institute for Biological Studies in La Jolla, California since 1993. Since 2005 he is also the Director of the Center for Regenerative Medicine in Barcelona. Dr. Izpisua Belmonte's research interests are focused on the understanding of stem cell biology, organ and tissue development and regeneration. He has helped to uncover the role of homeobox genes in limb patterning and specification, as well as the identification of the molecular mechanisms that determine how the different cell type precursors of internal organs are organized spatially along the embryonic left right axis. During the last few years, he has concentrated on studying the molecular basis implicated during organ regeneration in higher vertebrates, the differentiation of human stem cells into various tissues, and the molecular basis underlying aging and somatic cell reprogramming. He has published over 300 articles in internationally peer reviewed journals and book chapters in these areas. The ultimate goal of his research is to apply this knowledge towards the development of cell and gene based therapies as well as new molecules for the treatment of diseases. Dr. Izpisua Belmonte graduated from the University of Valencia, Spain with a Bachelor's degree in Pharmacy and Science and a Master's degree in Pharmacology and received his Ph.D. from the University of Bologna, Italy and the University of Valencia, Spain in 1987. He completed his postdoctoral work at the EMBL in Heidelberg, Germany and UCLA, Los Angeles, USA.

Ellen W. Clayton

Member

Ellen Wright Clayton, M.D., J.D., is an internationally respected leader in the field of law and genetics who holds appointments in both the law and medical schools at Vanderbilt, where she also co-founded and directed the Center for Biomedical Ethics and Society. She has published two books and more than 150 scholarly articles and chapters in medical journals, interdisciplinary journals and law journals on the intersection of law, medicine and public health. In addition, she has collaborated with faculty and students throughout Vanderbilt and in many institutions around the country and the world on interdisciplinary research projects, and helped to develop policy statements for numerous national and international organizations. She currently chairs the Paediatric Platform of the international Public Population Program in Genomics. An active participant in policy debates, she has advised the National Institutes of Health as well as other federal and international bodies on an array of topics ranging from children's health to the ethical conduct of research involving human subjects. Professor Clayton has worked on a number of projects for the National Academy of Medicine, of which she is a member of the Executive Committee of its National Advisory Council, chair of the Board on Population Health and Public Health Practice, and was chair of its committee to define myalgic encephalomyelitis/chronic fatigue syndrome. She is also a member of the National Academies' Report Review Committee. She is an elected Fellow of the American Academy for the Advancement of Science.

Barry S. Collier

Member

Barry S. Collier, M.D., is the Physician in Chief, Vice President for Medical Affairs, David Rockefeller Professor, and Allen and Frances Adler Laboratory of Blood and Vascular Biology at Rockefeller University. He is a leader in investigating platelet physiology, vascular biology and adhesion phenomena in sickle cell disease. He produced monoclonal antibodies that inhibit platelet aggregation and adhesion of sickle red blood cells to the blood vessel walls. He played a leading role in development and clinical trials of one of the earliest monoclonal antibodies into a drug used to prevent thrombosis after coronary artery angioplasty and stent placement in humans. He has also identified mutations in genes that cause human bleeding disorders. Dr. Collier received the Pasarow Award in 2005, the Warren Alpert Foundation Award in 2001 and a National Research Achievement Award from the American Heart Association in 1998. He is a member of the National Academy of Medicine, the National Academy of Sciences and the American Academy of Arts and Sciences. Dr. Collier is a past president of the American Society of Hematology and was founding president of the Society for Clinical and Translational Science. He currently serves on the Institute of Medicine Board on Health Science Policy.

Dr. Collier received his B.A. from Columbia University in 1966 and his M.D. from the New York University School of Medicine in 1970. He completed his residency in internal medicine at Bellevue Hospital in New York City and received advanced training in hematology and clinical pathology at the National Institutes of Health. He was at Stony Brook University from 1976 to 1993, and from 1993 to 2001 he served as a professor of medicine and chairman of the department of medicine at Mount Sinai School of Medicine. Dr. Collier came to Rockefeller in 2001 as the first David Rockefeller Professor, head of the Laboratory of Blood and Vascular Biology, physician in chief of The Rockefeller University Hospital and vice president for medical affairs. Dr. Collier also serves as principal investigator of the university's Clinical and Translational Science Award, and director of The Rockefeller University Center for Clinical and Translational Science.

John H. Evans

Member

John H. Evans, Ph.D., is a Professor of Sociology at the University of California, San Diego. Dr. Evans earned his B.A. from Macalester College and his Ph.D. from Princeton. He has been a Post-doctoral Fellow at Yale, a visiting member of the Institute for Advanced Study in Princeton, NJ, and has held visiting professorial fellowships at the University of Edinburgh and the University of Muenster. His research concerns religion, culture, politics and science. He has published a book about the ethical debates about human genetic engineering in the second half of the 20th century. Another book examines what religious people in the U.S. think about reproductive genetic technologies. A recent book concerns how societal views can be included in public bioethical debates about issues like genetic modification. A forthcoming book examines what Americans think a human is, and how that relates to how we should treat each other. He is writing a book about what the relationship is between religion and science for American citizens. In addition to these books, Dr. Evans has written over 40 articles and book chapters on topics in religion, culture, politics and science.

Rudolf Jaenisch

Member

Rudolf Jaenisch, M.D., a Whitehead Founding Member, is a professor of biology of the Whitehead Institute at the Massachusetts Institute of Technology (MIT). He focuses on understanding epigenetic regulation of gene expression. Most recently, this work has led to major advances in the understanding of embryonic stem cells and “induced pluripotent stem” (IPS) cells, which appear identical to embryonic stem cells but can be created from adult cells without using an egg. In addition to its stem cell work, Dr. Jaenisch’s lab is investigating epigenetic mechanisms for certain types of cancer and for brain development, studying how conditions such as Rett Syndrome occur.

Dr. Jaenisch received his doctorate in medicine from the University of Munich in 1967. Before coming to Whitehead, he was head of the Department of Tumor Virology at the Heinrich Pette Institute at the University of Hamburg. He has coauthored more than 375 research papers and has received numerous prizes and recognitions, including an appointment to the National Academy of Sciences in 2003.

Jeffrey Kahn

Member

Jeffrey Kahn, PhD, MPH, is the inaugural Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics and Public Policy at the Johns Hopkins Berman Institute of Bioethics. He works in a variety of areas of bioethics, exploring the intersection of ethics and health/science policy, including human and animal research ethics, public health, and ethical issues in emerging biomedical technologies.

Prof. Kahn has served on numerous state and federal advisory panels, and he is currently chair of the Institute of Medicine (IOM) Board on Health Sciences Policy. He is co-principal investigator on an NIH “Center of Excellence” project to study the ethical, legal and social implications (ELSI) of genomic research examining the largely unexplored but crucial study of genomics as applied to infectious disease. He was the founding president of the Association of Bioethics Program Directors, a position he held from 2006-2010, and is an elected Fellow of The Hastings Center.

Prof. Kahn has published three books and over 115 articles in the bioethics and medical literature, and speaks frequently across the US and around the world on a range of bioethics topics. Prior to joining the faculty at Johns Hopkins, Prof. Kahn was Director of the Center for Bioethics at the University of Minnesota. His education includes a BA from UCLA, PhD from Georgetown University, and MPH from the Johns Hopkins Bloomberg School of Public Health.

Ephrat Levy-Lahad

Member

Ephrat Levy-Lahad, M.D., is a professor of internal medicine and medical genetics at the Hebrew University of Jerusalem and director of the Medical Genetics Institute at Shaare Zedek Medical Center in Jerusalem. She received her medical degree from the Hebrew University-Hadassah Medical School in Jerusalem, and is board-certified in internal medicine (Israel) and in clinical genetics and clinical molecular genetics (Israel and USA). Levy-Lahad's clinical laboratory includes cancer genetics diagnostics and a large preimplantation diagnosis service. Her research laboratory focuses on genetics of breast cancer, in particular the BRCA1 and BRCA2 genes, and on genetic and environmental factors that affect the risk associated with these mutations. She also studies application of genetic testing to population screening and large-scale prevention efforts. Another focus of her research is elucidating the genetic basis of rare diseases, including discoveries of novel genes for neurological phenotypes and for defects in ovarian development. Levy-Lahad is highly involved in bioethical aspects of genetic research, and is currently co-chair of the Israel National Bioethics Council. She is a member of Israel's National Council for Gynecology, Perinatal Medicine, and Genetics and the National Council for Digital Health Innovation. Internationally, she was a member of UNESCO's (United Nations Educational, Scientific, and Cultural Organization) International Bioethics Committee (2006-2009) and the International Society for Stem Cell Research's Task Force on the Clinical Translation of Stem Cells.

Robin Lovell-Badge

Member

Robin Lovell-Badge, Ph.D, is the Group Leader of The Francis Crick Institute. Dr. Lovell-Badge has had long-standing interests in the biology of stem cells, in how genes work in the context of embryo development, and how decisions of cell fate are made. Major themes of his current work include sex determination, development of the nervous system and pituitary, and the biology of stem cells within the early embryo. He is also very active in both public engagement and policy work, notably around stem cells, genetics, human embryo and animal research, and in ways science is regulated and disseminated. He was elected a member of EMBO in 1993, a Fellow of the Academy of Medical Sciences in 1999, and a fellow of the Royal Society in 2001. He has received the Louis Jeantet Prize for Medicine (1995), the Amory Prize (Awarded by the American Academy of Arts and Sciences) (1996), the Feldberg Foundation Prize (2008), and the Waddington Medal of the British Society for Developmental Biology (2010). He is also a Distinguished Visiting Professor at the University of Hong Kong (2009-2015) and the President of the Institute of Animal Technologists. Dr. Lovell-Badge obtained his BSc in zoology at University College, London in 1975, and his PhD in embryology at University College London in 1978.

Gary Marchant

Member

Gary Marchant, J.D., Ph.D., is the Lincoln Professor of Emerging Technologies, Law and Ethics at the Sandra Day O'Connor College of Law at Arizona State University (ASU). He is also a Professor of Life Sciences at ASU and Executive Director of the ASU Center for the Study of Law, Science and Technology. Professor Marchant has a Ph.D. in Genetics from the University of British Columbia, a Masters of Public Policy degree from the Kennedy School of Government, and a law degree from Harvard. Prior to joining the ASU faculty in 1999, he was a partner in a Washington, D.C. law firm where his practice focused on environmental and administrative law. Professor Marchant teaches and researches in the subject areas of environmental law, risk assessment and risk management, genetics and the law, biotechnology law, food and drug law, legal aspects of nanotechnology, and law, science and technology.

Jennifer Merchant

Member

Jennifer Merchant, Ph.D. in Political Science, is a Professor of Anglo-American Legal and Political Institutions at University Panthéon-Assas Paris II. She is a leading researcher in bioethical issues of comparative public policy, with expertise in comparative North American and European policy, politics, and regulation of medical technologies involving human reproduction. She is also an expert in French law and politics on embryo research and ART. Her academic interests include comparative public policy, reproduction, bioethics, civil society, science, and government. Dr. Merchant is member of the French National University Institute, the CERSA (Centre for the Study and Research of Administrative and Political Sciences), the Ethics Committee of INSERM, and the International Network on Feminist Approaches to Bioethics Association as well as FAB Country Representative for France. She has been Co-Editor-In-Chief of the *Revue Tocqueville / Tocqueville Review* since 2001, and member of the GEO (Global Ethics Observatory) / UNESCO since 2005.

Luigi Naldini

Member

Luigi Naldini, M.D., Ph.D., is Professor of Cell and Tissue Biology and of Gene and Cell Therapy at the University School of Medicine and the Scientific Director of the San Raffaele Telethon Institute for Gene Therapy, Milan, Italy. The San Raffaele-Telethon Institute for Gene Therapy (TIGET) is a joint-venture between the San Raffaele Scientific Institute and the Telethon Foundation established to perform innovative research on gene transfer and cell transplantation and translate its results into successful clinical application of gene and cell therapy for genetic diseases. Dr. Naldini's research has focused on gene therapy and his laboratory first described the use of hybrid lentiviral vectors for gene transfer into non-dividing cells. He has continued to investigate new gene transfer approaches and to exploit them to gain insights into fundamental biological processes, such as stem cell activity and tumor angiogenesis, and to develop new therapeutic strategies for treating genetic disease and cancer. His laboratory also continues to investigate approaches to better preserve and expand hematopoietic stem cells in culture to support their genetic manipulation and improve the safety and efficacy of ex vivo gene therapy, and continues to develop gene targeting approaches based on engineered Zinc Finger Nucleases to edit the genomic sequence. Dr. Naldini is President of the European Society of Gene and Cell Therapy and was awarded the European Research Council (ERC) Advanced Investigator Grant in 2009 and the Premio Sapio of the Italian Research (Health Area) in 2012. He received his M.D. and his Ph.D. in Cell and Tissue Biology from Torino University.

Duanqing Pei

Member

Duanqing Pei, Ph.D., is Professor and Director General, Guangzhou Institutes of Biomedicine and Health, Chinese Academy of Sciences. Dr. Pei joined the Medical Faculty at Tsinghua University in Beijing China in 2002 and moved to the newly formed Guangzhou Institutes of Biomedicine and Health in 2004. Prior to this appointment, he served as a faculty member at the University of Minnesota School of Medicine.

Dr. Pei studied the transcription regulation of hepatitis B virus (HBV) for his PhD thesis by identifying C/EBP as a repressor for HBV transcription and dissecting the transactivation domains in C/EBP. Then he shifted his research interest into the field of extracellular matrix remodeling by studying the structure and function of matrix metalloproteinases (MMPs). He cloned several novel members of the MMP family, uncovered the unique intracellular activation mechanism of MMPs with the proprotein convertase system, and the intracellular trafficking of membrane-bound MMPs. Upon returning to China, he once again changed his field of study and started working on pluripotency first and then reprogramming. The Pei lab in Tsinghua began to publish in the stem cell field on the structure and function of Oct4, Sox2, FoxD3, Essrb, and Nanog, and their interdependent relationship towards pluripotency. Based on the understanding of these factors, the Pei lab was the first in China to create mouse iPSCs using a non-selective system, and then improved the iPS process systematically. The Pei lab subsequently disseminated the iPS technology in China by providing not only resources, but also training workshops. Recent publications from the Pei lab includes the discovery of vitamin C as a potent booster for iPSC generation and a mesenchymal to epithelial transition initiates the reprogramming process of mouse fibroblasts. Now, his lab continues to explore new ways to improve iPS technology, dissect the reprogramming mechanisms driven by Oct4/Sox2/Klf4 or fewer factors, and employ iPSCs to model human diseases in vitro. Dr. Pei obtained his PhD from the University of Pennsylvania in 1991 and trained as a postdoctoral fellow at the University of Michigan.

Matthew Porteus

Member

Matthew Porteus, M.D., Ph.D., is Associate Professor of Pediatrics, Divisions of Stem Cell Transplantation and Regenerative Medicine, Hematology/Oncology, and Human Gene Therapy at Stanford School of Medicine. He completed his combined M.D., Ph.D. at Stanford Medical School with his Ph.D. focused on understanding the molecular basis of mammalian forebrain development with his Ph.D. thesis entitled “Isolation and Characterization of TES-1/DLX-2: A Novel Homeobox Gene Expressed During Mammalian Forebrain Development.” After completion of his dual degree program, he was an intern and resident in Pediatrics at Boston Children’s Hospital and then completed his Pediatric Hematology/Oncology fellowship in the combined Boston Children’s Hospital/Dana Farber Cancer Institute program. For his fellowship and post-doctoral research he worked with Dr. David Baltimore at MIT and CalTech where he began his studies in developing homologous recombination as a strategy to correct disease causing mutations in stem cells as definitive and curative therapy for children with genetic diseases of the blood, particularly sickle cell disease. Following his training with Dr. Baltimore, he took an independent faculty position at UT Southwestern in the Departments of Pediatrics and Biochemistry before again returning to Stanford in 2010 as an Associate Professor. During this time his work has been the first to demonstrate that gene correction could be achieved in human cells at frequencies that were high enough to potentially cure patients and is considered one of the pioneers and founders of the field of genome editing—a field that now encompasses thousands of labs and several new companies throughout the world. He has extensive experience with the major engineered nuclease platforms including zinc finger nucleases, TAL effector nucleases, and CRISPR/Cas9 nucleases. He has used genome editing strategies in a variety of different stem cells including hematopoietic stem and progenitor cells, neural stem cells, spermatogonial stem cells, human embryonic stem cells, and induced pluripotent cells. His research program continues to focus on developing genome editing by homologous recombination as curative therapy for patients with both genetic and non-genetic diseases. Clinically, Dr. Porteus attends at the Lucille Packard Children’s Hospital where he takes care of pediatric patients undergoing hematopoietic stem cell transplantation. Administratively, Dr. Porteus is the Associate Director of the Stanford Medical Scientist-Training Program where he oversees the admission and progress of students obtaining both M.D. and Ph.D. degrees at Stanford.

Janet Rossant

Member

Janet Rossant, Ph.D., is a Senior Scientist in the Developmental & Stem Cell Biology program at The Hospital for Sick Children and is a Professor in the Department of Molecular Genetics, and the Department of Obstetrics and Gynaecology at the University of Toronto. Her research focuses on understanding the genetic control of normal and abnormal development in the early mouse embryo using both cellular and genetic manipulation techniques. Her interests in the early embryo have led to the discovery of a novel placental stem cell type, the trophoblast stem cell. Dr. Rossant is also the Director of the newly formed Ontario Institute for Regenerative Medicine. She is actively involved in the international developmental and stem cell biology communities and has contributed to the scientific and ethical discussion on public issues related to stem cell research. She chaired the working group of the Canadian Institutes of Health Research on Stem Cell Research, which came up with guidelines for CIHR funded research in this area. Dr. Rossant trained at the Universities of Oxford and Cambridge, United Kingdom and has been in Canada since 1977, first at Brock University and then at the Samuel Lunenfeld Research Institute, Mount Sinai Hospital, Toronto, from 1985 to 2005.

Dietram A. Scheufele

Member

Dietram A. Scheufele, Ph.D., is the John E. Ross Professor in Science Communication and Vilas Distinguished Achievement Professor at the University of Wisconsin-Madison and in the Morgridge Institute for Research. He is also an Honorary Professor of Communication at the Technische Universität Dresden (Germany). His research focuses on shaping public attitudes toward science and technology, with a recent emphasis on the role that social media and other emerging modes of communication play in society. Dr. Scheufele has published extensively in the areas of public opinion, political communication, and public attitudes towards emerging technologies, including nanotechnology, synthetic biology, stem cell research, nuclear energy, and genetically modified organisms.

Scheufele has co-chaired the National Academies' Roundtable on Public Interfaces of the Life Sciences and the National Conference of Lawyers and Scientists, a joint committee of the American Association for the Advancement of Science and the American Bar Association. He is a former member of the Nanotechnology Technical Advisory Group to the U.S. President's Council of Advisors on Science and Technology, and past President of the Midwest Association for Public Opinion Research.

He is a fellow of the American Association for the Advancement of Science and the Wisconsin Academy of Sciences, Arts & Letters, and a member of the German National Academy of Science and Engineering. In the past, Scheufele has been a tenured faculty member at Cornell University, a Shorenstein fellow at Harvard University, and a Visiting Fellow at the Annenberg Public Policy Center of the University of Pennsylvania.

Ismail Serageldin

Member

Ismail Serageldin, Ph.D., is the Founding Director of the Bibliotheca Alexandrina (BA), the new Library of Alexandria, inaugurated in 2002. He also chairs the Boards of Directors for each of the BA's affiliated research institutes and museums. He is advisor to the Egyptian Prime Minister in matters concerning culture, science and museums. He serves as Chair or Member of a number of advisory committees for academic, research, scientific and international institutions and civil society efforts, including the Advisory Committee of the World Social Science Report for 2013, as well as the UNESCO-supported World Water Scenarios (2013) and Chairs the Executive Council of the World Digital Library (2010) and the executive council of the Encyclopedia of Life (2010) and the ICANN Panel for the review of the internet future (2013). He also co-chaired the African Union's high level panel for Biotechnology (2006) and again for Science, Technology and Innovation (STI) in 2012-2013. He has previously held positions including Vice President of the World Bank (1992-2000), and Chairman Consultative Group on International Agricultural Research (CGIAR, 1994-2000), founder and former Chairman of the Global Water Partnership (GWP, 1996-2000) and the Consultative Group to Assist the Poorest (CGAP), a microfinance program (1995-2000) and was professor of the International Savoirs Contre Pauvreté (Knowledge Against Poverty), at Collège de France, Paris, and distinguished professor at Wageningen University in the Netherlands.

He is a member of many academies, including the U.S. National Academy of Sciences (Public Welfare Medalist), the American Philosophical Society, the American Academy of Arts and Sciences, the World Academy of Sciences (TWAS), the World Academy of Arts and Sciences (WAAS), the European Academy of Sciences and Arts, the African Academy of Sciences, Institut d'Egypte (Egyptian Academy of Science), the Royal Belgian Academy, the Bangladesh Academy of Sciences, the Indian National Academy of Agricultural Sciences.

Dr. Serageldin has published over 100 books and monographs and over 500 papers on a variety of topics, including biotechnology, rural development, sustainability, and the value of science to society. He has hosted a cultural program on television in Egypt (over 130 episodes) and developed a TV Science Series in Arabic and English. He holds a Bachelor of Science Degree in Engineering from Cairo University and a Master's Degree and a Ph.D. from Harvard University and has received 34 honorary doctorates.

Sharon Terry

Member

Sharon Terry, M.A., is President and CEO of Genetic Alliance, a network of more than 10,000 organizations, of which 1,200 are disease advocacy organizations. Genetic Alliance engages individuals, families and communities to transform health. Ms. Terry is also the founding CEO of PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE), which affects Ms. Terry's two adult children. As co-discoverer of the gene associated with PXE, she holds the patent for ABCC6 to act as its steward and has assigned her rights to the foundation. She developed a diagnostic test and conducts clinical trials. She is the author of 140 peer-reviewed papers, of which 30 are PXE clinical studies.

Ms. Terry is also a co-founder of the Genetic Alliance Registry and Biobank. In her focus at the forefront of consumer participation in genetics research, services and policy, she serves in a leadership role on many of the major international and national organizations, including the Accelerating Medicines Partnership, Institute of Medicine (IOM) Science and Policy Board, the IOM Roundtable on Translating Genomic-Based Research for Health, the PubMed Central National Advisory Committee, the PhenX scientific advisory board, the Global Alliance for Genomics and Health, the International Rare Disease Research Consortium Executive Committee and as Founding President of EspeRare Foundation of Geneva, Switzerland. She is on the editorial boards of several journals and is an editor of Genome. 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 work in community engagement in 2006; the first Patient Service Award from the UNC Institute for Pharmacogenomics and Individualized Therapy in 2007; the Research!America Distinguished Organization Advocacy Award in 2009; and the Clinical Research Forum and Foundation's Annual Award for Leadership in Public Advocacy in 2011. In 2012, she became an honorary professor of Hebei United University in Tangshan, China, and also received the Facing Our Risk of Cancer Empowered (FORCE) Spirit of Empowerment Advocacy Award. She was named one of FDA's "30 Heroes for the Thirtieth Anniversary of the Orphan Drug Act" in 2013. In 2012 and 2013, Terry won \$400,000 in first prizes in three large competitions for the Platform for Engaging Everyone Responsibly (PEER). PEER was awarded a \$1M contract from PCORI in 2014.

Jonathan S. Weissman

Member

Jonathan Weissman, Ph.D., is a professor of cellular and molecular pharmacology at the University of California, San Francisco and an HHMI investigator. His research explores how cells ensure that proteins fold into their correct shape, as well as the role of protein misfolding in disease and normal physiology. He is also developing experimental and analytical approaches for exploring the organizational principles of biological systems and globally monitoring protein translation through ribosome profiling. A broad goal of his work is to bridge large-scale approaches and in depth mechanistic investigations to reveal the information encoded within genomes.

Keith R. Yamamoto

Member

Keith R. Yamamoto, Ph.D., is Vice Chancellor for Research, Executive Vice Dean of the School of Medicine, and Professor of Cellular and Molecular Pharmacology at the University of California San Francisco (UCSF). In these roles, he oversees strategic planning as well as research activities at UCSF's school of medicine. After earning a Ph.D. at Princeton, he came to UCSF in 1973. He served as chair of the Department of Cellular and Molecular Pharmacology from 1994 to 2003. Dr. Yamamoto is regarded as an international leader in studying the mechanisms of signaling and gene regulation by intracellular receptors. He is a member of the National Academy of Sciences and National Academy of Medicine.