



UCSF Weill Neuroethics Symposium

ANTICIPATING
ETHICAL
CONCERNS
IN A
NEW
ERA
OF
NEUROSCIENCE

January 28, 2020
UCSF Mission Bay

KEYNOTE SPEAKERS

Jennifer Doudna & Eric Topol

ALSO FEATURING

Gabe Aranovich / Jose Carmena / Joseph Fins / Sara Goering / Hank Greely /
Kate Rankin / Stephan Sanders / Katherine Scangos / Anna Wexler / Laurie Zoloth

SPECIAL REMARKS BY

Sam Barondes & Stephen Hauser

Anticipating Ethical Concerns in a New Era of Neuroscience

Ongoing advances in neuroscience hold tremendous promise for reducing the burden of neurologic and psychiatric diseases, and may fundamentally change how we understand ourselves. The UCSF Weill Institute for Neurosciences was established to foster translational research in neuroscience, bringing new approaches and interventions to address the problems of patients with diseases of the brain. Given the complexity of the brain and the centrality of brain function to who we are, these efforts also pose deep ethical, legal and conceptual questions. To anticipate and address these problems, we are inviting input from leaders in many different fields.

The mission of this symposium is to better prepare the neurosciences community to anticipate and address neuroethical concerns arising from their work, and prepare for broader public engagement with these issues.

Schedule of Events

- 8:30AM **Introductory Remarks**
Stephen Hauser
- 8:45AM **Panel One | Neurogenetics & Parenthood**
- HEADLINE ADDRESS
Jennifer Doudna
- RESPONSE AND PERSPECTIVES
Stephan Sanders | Anticipated Uses in Autism
Hank Greely | Neurogenetics and Law
Laurie Zoloth | Religion and Values
- 10:15AM Break
- 10:30AM **Panel Two | Neuromodulation Roundtable**
- USE CASES AND PERSPECTIVES
Jose Carmena | Engineering and Industry
Katherine Scangos | Mood Disorder
Joseph Fins | Disorders of Consciousness
Sara Goering | Brain-Computer Interfaces
- 12:00PM Lunch Break
- 1:45PM **Panel Three | Patient Data in the Digital Age**
- HEADLINE ADDRESS
Eric Topol
- RESPONSE AND PERSPECTIVES
Kate Rankin | Bridging Research and Clinical Data
Anna Wexler | Ethics and Regulation
Gabe Aranovich | Industry Perspective
- 3:15PM **Concluding Remarks**
Sam Barondes | Shared Themes and Implications for Public Engagement
- 3:45PM **Reception**

Panel One

Neurogenetics & Parenthood

Moderated by:
Winston Chiong, MD PhD

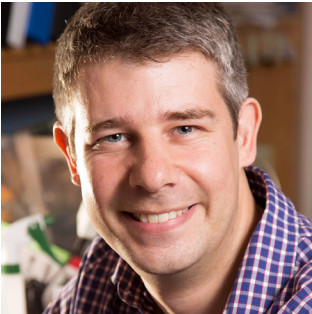


Recent years have brought tremendous advances in genetics and genomics, exemplified by the development of CRISPR-based gene editing. These techniques herald new possibilities for patients with dreaded neurological and psychiatric conditions, but have also enabled abuses that raise deep questions about the role of public engagement and regulation. The *Neurogenetics & Parenthood* panel will consider a range of genetic interventions including preimplantation genetic testing, gene editing and modifying gene expression, across which the development of therapeutic applications to treat or prevent disease could also enable non-therapeutic or enhancement applications. Parents with genetic neuropsychiatric conditions, but also neurologically typical parents, will increasingly be faced with consequential decisions about their children's cognitive and functional futures, often with incomplete or only probabilistic information. Our panelists will consider the broad ramifications of such control over the genetic inheritance of future generations, including scientific, legal, societal and religious perspectives.



Jennifer Doudna

Jennifer Doudna, PhD is the Li Ka Shing Chancellor's Chair and a Professor in the Departments of Chemistry and of Molecular and Cell Biology at UC Berkeley, and an Investigator of the Howard Hughes Medical Institute. Her co-discovery of CRISPR-Cas9 genetic engineering technology, with Emmanuelle Charpentier, has changed human and agricultural genomics research forever. In addition to her scientific achievements, Doudna is also a leader in public discussion of the ethical and other implications of genome editing for human biology and societies. In 2015, Doudna was named by Time Magazine as one of the 100 most influential people in the world.



Stephan Sanders

Stephan Sanders, BMBS PhD is an Associate Professor in the Department of Psychiatry at UCSF. He is a geneticist and pediatrician who works on the genetics of childhood neurodevelopmental disorders, in particular Autism Spectrum Disorder (ASD). His lab specializes in bioinformatics, including microarray, exome sequencing, and whole-genome sequencing to identify genetic loci, map genomic architecture, and understand the sex bias seen in ASD. One major goal is to identify specific genes that contribute to these disorders, for example the sodium channel gene *SCN2A* is commonly mutated in ASD, as an entrée into the underlying biology.



Hank Greely

Henry T. Greely, JD is the Deane F. and Kate Edelman Johnson Professor of Law and Professor, by courtesy, of Genetics at Stanford University. He specializes in ethical, legal, and social issues arising from the biosciences. He is a founder and immediate past President of the International Neuroethics Society; directs Stanford's Center for Law and the Biosciences; chairs the California Advisory Committee on Human Stem Cell Research; and serves on the National Academy of Sciences Committee on Climate Intervention Strategies that Reflect Sunlight to Cool Earth. He is a member of the NIH BRAIN Initiative's Multi-Council Working Group, whose Neuroethics Division he co-chairs. He published *The End of Sex and the Future of Human Reproduction* (Harvard University Press) in 2016.



Laurie Zoloth

Laurie Zoloth, PhD is the Margaret E. Burton Professor of Religion and the Senior Advisor to the Provost for Programs in Social Ethics at the University of Chicago. Previously, she founded and directed the Program in Jewish Studies at San Francisco State University. She is past President of the American Academy of Religion and the American Society for Bioethics and Humanities, and past Vice President of the Society for Jewish Ethics. She has served on the National Recombinant DNA Advisory Board, the NASA Advisory Council, the Executive Committee of the International Society for Stem Cell Research, and was the founding Chair of the Howard Hughes Medical Institute's Bioethics Advisory Board. She is the co-editor of six books and the author of *Health Care and The Ethics of Encounter* (University of North Carolina Press).

Panel Two

Neuromodulation

Roundtable

Moderated by:
Vikaas Sohal, MD PhD



Deep brain stimulation has been successfully used to treat Parkinson's disease for decades. Recent years have seen many attempts (both successful and unsuccessful) to use similar treatments for many conditions including depression, obsessive-compulsive disorder, epilepsy, and minimally conscious states. Many of these efforts include more advanced technologies, for example closed-loop approaches in which neural activity is recorded in order to trigger stimulation at specific times. The *Neuromodulation Roundtable* panel will discuss emerging opportunities and challenges related to these new treatments. The panel will include leaders in developing new technologies for brain stimulation, using these technologies to treat depression, and studying the neuroethics of brain stimulation-based intervention for movement disorders and disorders of consciousness. The panel will focus on the implications of having brain activity measured by a device, rather than a doctor or patient, determine when stimulation is delivered. Other topics we may consider are balancing potential therapeutic and adverse effects of stimulation, managing stimulation-induced changes in the brain over time, and how patients experience stimulation-driven changes in their brain function.



Jose Carmena

Jose M. Carmena, PhD is the Chancellor's Professor in the Department of Electrical Engineering and Computer Sciences, and the Helen Wills Neuroscience Institute, at UC Berkeley; and Co-Director of the Center for Neural Engineering and Prostheses at UC Berkeley and UCSF. His research program in neural engineering and systems neuroscience is aimed at understanding the neural basis of sensorimotor learning and control, and at building the science and engineering base that will allow the creation of reliable neuroprosthetic systems for the severely disabled.



Katherine Scangos

Katherine Scangos, MD PhD is an Assistant Professor and Co-Director of the TMS and Neuromodulation Clinic in the Department of Psychiatry at UCSF. Her research focuses on understanding the oscillatory changes within cortico-limbic brain networks that lead to disruptions in mood and cognition, and how we can detect and modulate this activity to reduce disease burden. Her goal is to combine neuromodulatory techniques with neurophysiology and imaging in a clinical research setting to examine the dynamics of neurons within neural networks important for normal brain function. She aims to translate these findings directly into novel closed-loop therapies for patients with refractory mental illness.



Joseph Fins

Joseph J. Fins, MD is the E. William Davis, Jr., MD Professor of Medical Ethics, Professor of Medicine, and Chief of the Division of Medical Ethics at Weill Cornell Medicine; the Solomon Center Distinguished Scholar in Medicine, Bioethics and the Law at Yale Law School; and a member of the Adjunct Faculty of Rockefeller University. He has authored more than 400 publications including co-authorship of the 2007 *Nature* paper describing the first use of deep brain stimulation in the minimally conscious state; he is also the author of *Rights Come to Mind: Brain Injury, Ethics and The Struggle for Consciousness* (Cambridge University Press).



Sara Goering

Sara Goering, PhD is Associate Professor of Philosophy and in the Program on Ethics, and co-leads the Neuroethics Research Thrust at the Center for Neurotechnology at the University of Washington. Her teaching includes courses on medical ethics, philosophy of disability, feminist philosophy, and philosophy of medicine. She also discusses philosophy with children in Seattle public schools, through her role as Program Director for the UW Center for Philosophy of Children. With Eran Klein, she leads a research program on brain-computer interfaces and human agency.

Panel Three

Patient Data in the Digital Age

Moderated by:
Jalayne Arias, JD



Jon VanLeeuwen, PhD



We now live in a digital age. This shift has impacted nearly every aspect of our daily lives and although the transformation in healthcare has been slower, the drive towards more precise, effective, and personalized care will be fueled by data. Yet, collecting, using and sharing data responsibly creates a range of unique ethical challenges. The *Patient Data in the Digital Age* panel will explore emerging tensions between the value of data to transform neuroscience and medicine and the challenges to pursue this ethically and responsibly in a new era of digital medicine. The panelists will share their visions of how various types of patient and research data, especially when coupled with advances in artificial intelligence, may provide opportunities to advance neurological and psychiatric health. The speakers will offer insights on engaging patients around data ownership and privacy, using data to inform clinical decisions and industry partnerships that drive therapy development, and the regulatory challenges and unintended consequences of delivering care in an increasingly digital world.



Eric Topol

Eric Topol, MD is the Founder and Director of the Scripps Research Translational Institute, Professor of Molecular Medicine, and Executive Vice President of Scripps Research. He is a member of the National Academy of Medicine, is one of the 10 most cited researchers in medicine, and was voted the most influential physician leader in a national poll conducted by Modern Healthcare. He leads major NIH grants in precision medicine (enrolling 1 million US participants) and promoting innovation in medicine, and was commissioned by the UK to lead planning for the National Health Service's integration of AI and new technologies. In addition to editing several textbooks, he is the author of *The Creative Destruction of Medicine*, *The Patient Will See You Now*, and *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again* (all from Basic Books).



Kate Rankin

Katherine Rankin, PhD is a Professor in the Department of Neurology at UCSF who investigates the neuropsychological and neurologic underpinnings of human socioemotional behavior in aging and neurodegenerative disease. She also specializes in the development of strategies for aggregating cross-disciplinary data and analytic processes across labs and institutions to facilitate scientific collaboration, and has led the data/biostatistics and bioinformatics cores of a number of center grants and privately funded research consortia. She is a leader in the UCSF-wide Precision Medicine initiative, and advises on a number of UCSF committees and boards promoting digital health and computational strategies for improving research and clinical care.



Anna Wexler

Anna Wexler, PhD is an Assistant Professor in the Department of Medical Ethics and Health Policy at the Perelman School of Medicine at the University of Pennsylvania. She is the Principal Investigator of the Wexler Lab, which studies ethical, legal and social issues surrounding emerging technology, with a particular focus on do-it-yourself and direct-to-consumer medicine and science. She is the recipient of a 2018 NIH Director's Early Independence Award. Prior to her PhD, she co-directed and co-produced the feature documentary *Unorthodox* (2013).



Gabe Aranovich

Gabriel Aranovich, MD is a digital health executive with a background in medicine and neuroscience. He currently serves as Medical Director and Co-Founder of The Clinic, an innovative mental health clinic with locations across the San Francisco Bay Area. Previous roles include Chief Clinical Officer at Mindstrong, where he launched and scaled the company's novel measurement-based care model, and Medical Director of Lyra Health, where he led the creation of a nationwide network of evidence-based clinicians. He completed his clinical training at Stanford and UCSF and continues to maintain a small psychiatry practice.

Introductory & Closing Remarks



Stephen Hauser

Stephen L. Hauser, MD is the Robert A. Fishman Distinguished Professor of Neurology at UCSF and Director of the UCSF Weill Institute for Neurosciences; previously, he was Chair of the UCSF Department of Neurology for 25 years. His research has advanced our understanding of the genetic basis, immune mechanisms, and treatment of multiple sclerosis (MS), including developing the first therapy of proven value for progressive MS. He is a member of the National Academy of Medicine, a Fellow of the American Academy of Arts and Sciences and the American Academy of Physicians, past President of the American Neurological Association, and past Editor-in-Chief of *Annals of Neurology*. He is an editor of the medical textbook *Harrison's Principles of Internal Medicine*. He also served the Obama administration as a member of the Presidential Commission for the Study of Bioethical Issues.



Sam Barondes

Samuel Barondes, MD is Jeanne and Sanford Robertson Professor and Director of the Center for Neurobiology and Psychiatry at UCSF; previously, he has served as Chair of the UCSF Department of Psychiatry and Director of the Langley Porter Psychiatric Institute. He is a member of the National Academy of Medicine, a Fellow of the American Academy of Arts and Sciences, a founding member and past President of the McKnight Endowment Fund for Neuroscience, and a past Chair of the NIMH Board of Scientific Counselors. In addition to his 200 research publications, he has edited two academic books and written five books for a general audience.



Sanford I. "Sandy" Weill and Joan Weill

About the Weill Neurosciences Symposium Series

The Weill Neurosciences Symposium Series brings together leaders in science and medicine to showcase innovative research, inspiring ideas, and highlight new paths toward discovery. Each symposium takes on a different theme, offering a renewed focus on key issues and disease areas across the neurosciences.

