



Advancing Data-Driven Innovation for the Health of Women

OVERVIEW

9th ANNUAL VIVIAN W. PINN SYMPOSIUM:

Advancing Data-Driven Innovation for the Health of Women

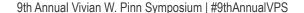
The Vivian W. Pinn Symposium honors the first full-time Director of the National Institutes of Health (NIH) Office of Research on Women's Health (ORWH), Vivian W. Pinn, M.D., and is held every year during National Women's Health Week. This event serves as a critical forum for experts across sectors to communicate and collaborate for the advancement of women's health.

The title of this year's symposium is "Advancing Data-Driven Innovation for the Health of Women." The symposium focuses on how data science skills, resources, and training can build capacity for interdisciplinary data analyses.

Flash talks from NIH program staff will highlight NIH data resources and repositories. Raquel Hill, Ph.D., Chair of Computer and Information Sciences and Professor, Spelman College, will provide the capstone address, "Advancing Data Innovations for Health Improvements: Possibilities and Pitfalls." Experts in data science, precision medicine, and community-centered research will present cutting-edge approaches to women's health in context, followed by a moderated panel discussion.

The objectives of the symposium are to:

- Data Dissemination. Highlight quantitative and qualitative federal data resources that can be used to understand women's health in context.
- Data Literacy. Familiarize attendees with key concepts in data science and social determinants of health.
- **Real-World Science.** Highlight applications of data science-based applications to community-centered projects.
- Data Privacy. Review key issues and opportunities related to data privacy and accessibility.



About Vivian W. Pinn, M.D.

Founding Director (Retired), ORWH Senior Scientist Emerita, Fogarty International Center, NIH



Dr. Vivian W. Pinn was the inaugural full-time Director of ORWH, from 1991 until her retirement in 2011. Dr. Pinn was also NIH's Associate Director for Research on Women's Health from 1994 until her retirement. Under her leadership, this new office led the implementation of NIH inclusion policies for women and minorities in clinical research, developed the first and several subsequent national strategic plans for women's health research, and established many new research funding initiatives and career development programs, including interdisciplinary initiatives, in collaboration with NIH Institutes and Centers. During that time, she also established and co-chaired the NIH Working Group on Women in Biomedical Careers with the NIH Director. She has since been named a Senior Scientist Emerita at NIH's Fogarty International Center. She has presented her perceptions of women's health research, health disparities, and challenges in biomedical careers for women and people of color to national and international audiences and has served as a mentor to hundreds of young women and men of all races. A special tribute by Senator Olympia Snowe on Dr. Pinn's retirement was published in the Congressional Record in November 2011. Senator Snowe commended Dr. Pinn's contributions during her NIH tenure. At the time of Dr. Pinn's retirement, the Association of American Medical Colleges honored her with a Special Recognition Award for exceptional leadership over a 40-year career.

She earned her M.D. in 1967 from the University of Virginia School of Medicine, the only woman and only minority in her class. She completed her postgraduate training in pathology at Harvard University's Massachusetts General Hospital.

She came to NIH from the Howard University College of Medicine, where she had been Professor and Chair of the Department of Pathology since 1982, the third woman in the United States to hold such an appointment and the first African American woman to do so. Dr. Pinn also previously held teaching appointments in pathology at Harvard Medical School and Tufts University, where she was also Assistant Dean for Student Affairs. Her professional area of focus in pathology was immunopathology, specifically renal and autoimmune diseases, and transplant pathology. She now holds the position of Professor at the University of South Florida's Institute for Advanced Discovery & Innovation.

She is a fellow of the American Academy of Arts and Sciences and was elected to the Institute of Medicine (now the National Academy of Medicine) in 1995. She served several terms on the National Academies' Committee on Women in Science, Engineering, and Medicine and was a member of the National Academies committee that prepared the 2020 report titled Promising Practices for Addressing the Underrepresentation of Women in Science, Engineering, and Medicine: Opening Doors. She is also a member of the National Academies' Roundtable on Black Men and Black Women in Science, Engineering, and Medicine. Dr. Pinn has written more than 200 scientific publications and book chapters, including forewords, and has given more than 500 keynote speeches, lectures, and presentations since 1991.

A native of Lynchburg, Virginia, and educated in segregated public schools, Dr. Pinn has received 17 honorary degrees of science, law, and medicine. The University of Virginia School of Medicine named one of its four advisory medical student colleges the Pinn College in her honor. In 2011, the Tufts University School of Medicine announced the Vivian W. Pinn Office of Student Affairs, and her former medical students dedicated a scholarship in her name, the Vivian W. Pinn Scholarship Fund, to give needy students an opportunity to study medicine at Tufts. Further, in December 2016, the University of Virginia School of Medicine announced the inaugural Pinn Scholars program to support and recognize midlevel faculty members for their efforts to take their research in novel directions. Dr. Pinn received the Alumna Achievement Award from Wellesley College and was an Alumna Trustee there. She has held leadership positions in many professional organizations, including as the 88th President of the National Medical Association (NMA), and is currently Chair of the NMA Past Presidents Council. Dr. Pinn serves on the boards of trustees/advisors of Thomas Jefferson University, the Sidney Kimmel Cancer Center at Jefferson Health, the Tufts University School of Medicine, and the KGI School of Medicine.

Dr. Pinn has received more than 300 honors and awards. She was elected to Modern Healthcare's Hall of Fame, the first African American woman to be so honored, and was also a recipient of the New York Academy of Medicine Medal for Distinguished Contributions in Health Policy. Other honors include a special lifetime achievement award from the Drexel University College of Medicine's Institute for Women's Health in 2017 and service as the 2017–18 Leader-in-Residence at the Jepson School of Leadership Studies of the University of Richmond. In 2019, she was presented with the John D. Thompson Distinguished Visiting Fellow Award by the Yale University School of Public Health.

She more recently received the 2020 American Medical Association's Distinguished Service Award for her leadership in women's health, as well as the 2020 Alma Dea Morani Award from the Women in Medicine Legacy Foundation and the New York Academy of Medicine. She was also awarded the 2021 Distinguished Service Award from the Association of Pathology Chairs and was elected a 2021 Fellow of the American Association for the Advancement of Science. She was also included in Hearst's "Lift Every Voice" project, a celebration of Black lives.

Research!America awarded her the Outstanding Achievement in Public Health Award as one of its 2022 Advocacy Awards honorees. In honor of her efforts as a faculty member of the Tufts University medical school, Tufts University selected her as one of eight influential Black leaders for its 2022 project named "Leading While Black: A Legacy of Transformational Black Leadership at Tufts University."

NIH, NMA, and the National Women's Health Congress have established lectures in women's health in her name. Her oral history is included in the National Library of Medicine's exhibit on women physicians, "Changing the Face of Medicine"; in the University of Virginia's project named "Explorations in Black Leadership," conducted by Julian Bond; and in the HistoryMakers collection, which is now housed in the Library of Congress.

AGENDA—VIRTUAL EVENT

Janine Austin Clayton, M.D., FARVO Director, NIH Office of Research on Women's Health **Opening Remarks** 12:00-12:15 p.m. Associate Director for Research on Women's Health, NIH Flash Talks: NIH Data Resources and **NIH Program Staff** 12:15-1:00 p.m. Repositories **Capstone Speaker:** Raquel Hill, Ph.D. Advancing Data Innovations Chair of Computer and Information Sciences and 1:00–1:35 p.m. for Health Improvements: Professor, Spelman College Possibilities and Pitfalls

1:35–1:45 p.m. **Q&A** Moderator: Dina Paltoo, Ph.D., M.P.H. National Library of Medicine, NIH

1:45-1:55 p.m. - Break

Jenna Norton, Ph.D., M.P.H. **Overview of Panel Session and** National Institute of Diabetes and Digestive and 1:55-2:00 p.m. **Speaker Introductions** Kidney Diseases, NIH From Story to Data, From Data Melissa Buffalo, M.S. 2:00-2:15 p.m. to Healing: Data Sovereignty CEO, American Indian Cancer Foundation for Native Women Fostering Data-Driven Rochelle Prosser, RN, CLNC Decisions for Patients and 2:15-2:30 p.m. Founder, Orchid Healthcare Solutions Caregivers Advancing Precision Women's Health: Empowering Impacted Alex Carlisle, Ph.D. 2:30-2:45 p.m. Populations to Transform Founder, Chairman, and CEO Women's Health through AI National Accelerator for Discovery in Precision Health and Data Innovation

AGENDA (CONTINUED)

2:45–3:00 p.m.	Computational Biology for Women's Health	Liat Shenhav, Ph.D. Assistant Professor, Department of Microbiology; Assistant Professor, Department of Obstetrics and Gynecology, NYU Grossman School of Medicine
3:00–3:15 p.m.	Data Privacy and Data Transparency: Ethical, Legal, Regulatory, and Policy Issues	Pilar Ossorio, Ph.D., J.D. Professor of Law and Bioethics University of Wisconsin-Madison
3:15–3:45 p.m.	Panel Discussion	Moderator: Vivian Ota Wang, Ph.D. Deputy Director, ORWH
3:45-4:00 p.m.	Closing Remarks	Vivian W. Pinn, M.D. Founding Director (Retired), ORWH Senior Scientist Emerita, Fogarty International Center, NIH



OPENING REMARKS

Janine Austin Clayton, M.D., FARVO

Associate Director for Research on Women's Health Director, ORWH, NIH



Dr. Janine A. Clayton was appointed Associate Director for Research on Women's Health and Director of ORWH in 2012. Dr. Clayton has strengthened NIH support for research on diseases, disorders, and conditions that affect women. She is the architect of the NIH policy requiring scientists to consider sex as a biological variable across the research spectrum, a part of NIH's initiative to enhance reproducibility, rigor, and transparency. In 2021, Dr. Clayton was elected to the Board of Directors of the American Association for the Advancement of Science.

Before joining ORWH, Dr. Clayton was the Deputy Clinical Director of the National Eye Institute (NEI). As a board-certified ophthalmologist, Dr. Clayton has interest in research on autoimmune ocular diseases and sex differences in health and disease. Dr. Clayton has a particular interest in ocular surface disease and discovered a novel form of disease associated with premature ovarian insufficiency that affects young women, setting the stage for her commitment to rigorous, thoughtful exploration of sex differences in health and disease. She is the author of more than 120 scientific publications, journal articles, and book chapters. Her clinical research has ranged from randomized controlled trials of novel therapies for immunomediated ocular diseases to studies on the development of digital imaging techniques for the anterior segment.

Dr. Clayton, a native Washingtonian, received her undergraduate degree with honors from Johns Hopkins University and her medical degree from the Howard University College of Medicine. She completed a residency in ophthalmology at the Medical College of Virginia. Dr. Clayton completed fellowship training in cornea and external disease at the Wilmer Eye Institute at Johns Hopkins Hospital and in uveitis and ocular immunology at NEI.

Vivian Ota Wang, Ph.D.

Deputy Director, ORWH, NIH



Psychologist, geneticist, and genetic counselor, Dr. Vivian Ota Wang has experiences that spans biomedical, psychological, genomic, nanoscale, and data sciences. She applies her expertise and scientific leadership as the Deputy Director of ORWH.

Previously, she was a Lead at the NIH Office of Data Science Strategy where she envisioned and spearheaded the RADx Tribal Data Repository, the first NIH sovereignty-based research data repository. Her other public service includes the inaugural Deputy Director of the Office of Data Sharing at the National Cancer Institute; Program Director for Data Access and Sharing and Ethical, Legal, and Social Implications (ELSI) Research Program at the National Human Genome Research Institute; Senior Advisor to the Director of the NIH Office of Behavioral and Social Sciences Research; and Executive Office of the President's National Science and Technology Council under the Bush and Obama administrations where she developed public engagement and ELSI guidance for nanoscience/nanotechnology.

Prior to public service, she was a genetic counselor at the University of Colorado and held tenure-track faculty positions at Rutgers, Arizona State, and Vanderbilt universities. Her clinical expertise is in congenital and acquired disabilities, traumatic brain injury, and bereavement. Her accomplishments are recognized by university, professional, and government awards. She earned a B.A. in biology (Colorado College), an M.S. in genetic counseling (University of Colorado), and an M.Phil. and Ph.D. in counseling psychology (Columbia University). She is an American Medical Association Fellow (American College of Medical Genetics); a diplomate of the American Psychological Association, American Board of Medical Genetics, and American Board of Genetic Counseling; and a licensed psychologist.

CAPSTONE SPEAKER

Raquel Hill, Ph.D.

Chair of Computer and Information Sciences and Professor, Spelman College, Atlanta, GA

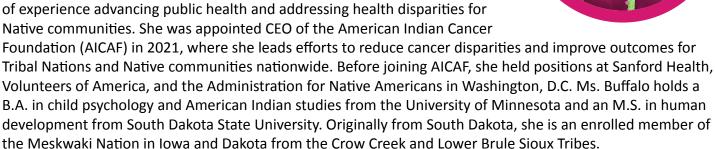


Dr. Raquel Hill is Professor and Chair of the Computer and Information Sciences Department at Spelman College. Prior to joining Spelman, Dr. Hill was an Associate Professor of Computer Science and Director of Cybersecurity Academic Programs within the School of Informatics, Computing, and Engineering at Indiana University, Bloomington. She has been awarded millions of dollars in funding in cybersecurity, data privacy, policy, and computer science education from various agencies, including the National Science Foundation (NSF), Hewlett Foundation, Reboot Representation Tech Coalition, and Google Foundation. She is Spelman's Principal Investigator for the NSF-funded Distributed Confidential Computing Center, Cyber Policy, Cybersecurity Clinic, and Computer Science Education Activities. Dr. Hill's research spans the areas of trust and security for distributed computing environments and data privacy. She earned her B.S. and M.S. degrees in computer science from the Georgia Institute of Technology and her Ph.D. in computer science from Harvard University.

BIOGRAPHIES Melissa Buffalo, M.S.

CEO, American Indian Cancer Foundation

Ms. Melissa Buffalo, a citizen of the Meskwaki Nation, has nearly 20 years of experience advancing public health and addressing health disparities for Native communities. She was appointed CEO of the American Indian Cancer





Founder, Chairman, and CEO, National Accelerator for **Discovery in Precision Health**

Dr. Alex Carlisle holds a Ph.D. in biochemistry and molecular biology from Howard University and received his postdoctoral training at NIH. His work has

focused on developing and applying innovative data analytic approaches to understanding disease progression and how to prevent it. While at NIH, he developed bioinformatic tools for analyzing gene expression data in prostate cancer and Parkinson's disease; later, while at Northrop Grumman Health, he helped to develop a prototype for near real-time analysis of integrated genomic and electronic health record data in the cloud, and later led the development of a prototype Precision Oncology Analytics Platform for predicting tumor stage and health outcome in neuroblastoma patients. Dr. Carlisle is the Chief Scientific Officer and CEO of the National Accelerator for Discovery in Precision Health, a national nonprofit that leverages advance computational and data science technologies such as artificial intelligence and machine learning in support of its mission to improve the health of the United States.



Pilar Ossorio, Ph.D., J.D.

Professor of Law and Bioethics University of Wisconsin-Madison

Dr. Pilar N. Ossorio is Professor of Law and Bioethics at the University of Wisconsin and an Investigator and Head of the Ethics Program at the Morgridge Institute for Research. Her research focuses on governance and ethics of emerging technologies, governance and ethics of research involving humans, and the uses of race and ethnicity categories in biomedical research. She directs the Research Ethics Consultation Service that serves the University of Wisconsin and affiliated research entities. She has served on the Secretary's Advisory Committee for Human Research Protections; the National Human Genome Research Advisory Council; the National Heart, Lung, and Blood Advisory Council; the Novel and Exceptional Technology and Research Advisory Committee (advisory to the NIH Director); several committees for the National Academies of Sciences, Engineering and Medicine; and advisory committees for Health Canada.



Rochelle Prosser, RN, CLNC

Founder, Orchid Healthcare Solutions

Ms. Rochelle Prosser is an Army mom and a dedicated health care founder who has turned her family's struggles with cancer into a mission to help others.

As a parent and wife of two cancer survivors, she spent nine years seeking a viable solution for one of her family members. This experience led her to create the Prosser Cancer Treatment Library, a comprehensive database of cancer treatment options aimed at reducing the stress and information

gaps for other families.

Through her company, Orchid Healthcare Solutions, Ms. Prosser provides nursing-dedicated electronic health

Through her company, Orchid Healthcare Solutions, Ms. Prosser provides nursing-dedicated electronic health records, cancer education, resources, and health care system navigation to patients, oncology providers, and industry partners. She is a founding member of the President's Cancer Panel of the Cancer Moonshot Initiative and remains an active member of numerous professional organizations.

Liat Shenhav, Ph.D.

Assistant Professor, Department of Microbiology; Assistant Professor, Department of Obstetrics and Gynecology NYU Grossman School of Medicine



Dr. Liat Shenhav is an Assistant Professor at the Institute for Systems Genetics and the Department of Microbiology at the Grossman School of Medicine, with affiliations in the Department of Computer Science at the Courant Institute for Mathematical Sciences and the Center for Data Science. Dr. Shenhav is the Principal Investigator of the Shenhav Lab, a computational biology research group dedicated to developing mathematical models and artificial intelligence algorithms to improve the health of women and children, with a focus on fertility, pregnancy, and lactation. Before joining NYU, Dr. Shenhav was an independent research fellow at the Center for Studies in Physics and Biology at Rockefeller University. She holds a B.Sc. and M.Sc. in mathematics and statistics from Tel Aviv University and a Ph.D. in computer science from the University of California, Los Angeles.



The NIH Office of Research on Women's Health (ORWH)

Established in September 1990, the Office of Research on Women's Health (ORWH) serves as the focal point for health research at the National Institutes of Health (NIH). For nearly 35 years, ORWH has worked across NIH and beyond to advance our understanding of biological and social factors influencing women's health and disease, support individuals in biomedical careers, and stimulate research to improve overall health.