

30 YEARS OF THE GENOME

Integrating and Applying ELSI Research

[ELSI Virtual Forum](#) • June 15 and 16, 2020

WELCOME

Dear Colleagues,

Welcome to the first ELSI Virtual Forum! Despite the unprecedented and turbulent circumstances throughout the world, we are delighted to provide a platform to engage with substantive presentations and enriching debate on research addressing the ethical, legal and social implications (ELSI) of genetics and genomics.

Our theme: *30 Years of the Genome: Integrating and Applying ELSI Research* marks the beginning of the [ELSI Program at the National Human Genome Research Institute](#) in 1990. During this period, ELSI has emerged as a new multi-disciplinary and increasingly global field of inquiry. By calling out the themes of integration and application, we invite reflection on how ELSI research and scholarship impacts genetic and genomic research, clinical practice, and public policy. We hope that this two-day forum will catalyze lively discussion on these questions in the context of past, present and future ELSI research.

We are grateful to all of you who submitted proposals to the originally planned in-person meeting and we regret the cancellation of these presentations due to COVID-19. Our tentative plan is to hold the rescheduled 5th ELSI Congress in 2021 as an in-person, on-line or hybrid meeting. Abstracts accepted in 2020 that remain timely and unpublished may be re-submitted for consideration in 2021. Details of the new call for papers will be forthcoming.

We thank all who supported our original plans for the ELSI Congress and the ELSI Virtual Forum. We are particularly indebted to the work of our [Organizing Committee](#) and appreciate their dedication to this effort. Special gratitude goes out to Rachel Yarmolinsky and Sam Corder who worked tirelessly on the plans and operations on the congress and our pivot to the current program.

Finally, we stand in solidarity with all who are outraged at the ongoing injustice and structural racism that divides American society. The ELSI community that includes scholars, researchers, clinicians, policy makers, journalists, and advocates has a responsibility to lead a path forward towards justice. We hope the ELSI Virtual Forum will further the necessary work of confronting and addressing inequities through ELSI research and scholarship and commit us to a path that moves us towards this goal.

Warmest regards,

Sandra Soo-Jin Lee, PhD, Chief, Division of Ethics, Dept of Medical Humanities and Ethics, Columbia University

Mildred Cho, PhD, Associate Director, Stanford Center of Biomedical Ethics, Stanford University

The ELSI Virtual Forum is organized and supported by the Columbia University Division of Ethics, Stanford University, and the National Human Genome Research Institute

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SCHEDULE

Click on each title to see abstract and speaker information

Day 1 • MONDAY, JUNE 15 • EDT (GMT-4)

10:00 - 10:15 am	Welcome: Sandra Soo-Jin Lee, PhD and Mildred Cho, PhD
10:15 - 11:00 am	<u>Opening Keynote: Integrating ELSI and Genomics: Past, Present, and Future</u> Speakers: Eric Juengst, PhD; Pilar Ossorio, JD, PhD; Eric Green, MD, PhD Moderator: Amy McGuire, JD, PhD
11:00 – 11:30 am	Q&A with Audience and Panel
11:30 - 11:45 am	BREAK (15 minutes)
11:45am-12:30pm	<u>Panel 1: Studying America’s Eugenics Era through an ELSI Lens: Data, Context, and Relevance</u> Panelists: Natalie Lira, PhD; Nicole Novak, PhD, MSc; Elyse Thulin, MS; Alexandra Minna Stern, PhD
12:30 – 1:00 pm	Q&A with Audience and Panel
1:00 - 1:30 pm	BREAK (30 minutes)
1:30 - 2:40 pm	<u>Plenary 1: Polygenic Risk Scores & Behavioral Traits: Interrogating the Science & Ethics</u> Speakers: Dalton Conley, PhD; Steven Hyman, MD; Michelle Meyer, JD, PhD; Moderator: Paul Appelbaum, MD
2:40 - 3:00 pm	Q&A with Audience and Panel
3:00 - 3:15 pm	BREAK (15 minutes)
3:15 – 4:00 pm	<u>Panel 2: New Models for Ethical AI in Precision Medicine: Empirical and Normative ELSI Inquiry</u> Panelists: David Magnus, PhD; Pamela Sankar, PhD; Ariadne Nichol, BA Moderator: Mildred Cho, PhD
4:00 – 4:30 pm	Q&A with Audience and Panel
4:30 pm	Close of Day 1

FAQs

- Not registered? Please review [Code of Conduct Guidelines](#) before registering
- [Click here to register](#)
- [Click here to log in](#) to the meeting ([click here to call-in](#) to the meeting)
- Questions for panelists: Use the Q&A function
- Engage with attendees: write a note in the Chat
- Other questions? email info@elsicon2020.org

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Click on each title to see abstract and speaker information

Day 2 • TUESDAY, JUNE 16 • EDT (GMT-4)

10:00 - 10:15 am	Welcome: Sandra Soo-Jin Lee, PhD
10:15 - 11:00 am	<u>Plenary 2: CRISPR and Human Identity: Governing Germline Gene Editing</u> Speakers: Rosemarie Garland-Thomson, PhD; George Daley, MD, PhD; Bartha Knoppers, JD, PhD Moderator: Josephine Johnston, LLB, MBHL
11:00 – 11:30 am	Q&A with Audience and Panel
11:30 - 11:45 am	BREAK (15 minutes)
11:45am-12:30pm	<u>Panel 3: Engaging Participants as Partners: ELSI Considerations in Large-Scale Precision Medicine Research</u> Panelists: Alecia M. Fair, DrPH; Karriem Watson, DHSc, MS, MPH; Elizabeth Cohn, RN, PhD; Consuelo Wilkins, MD, MSCI
12:30 – 1:00 pm	Q&A with Audience and Panel
1:00 - 1:30 pm	BREAK (30 minutes)
1:30 - 2:15 pm	<u>Plenary 3: Ethical Frameworks for Research Collaboration with Indigenous Communities</u> Speakers: Chief Lynn Malerba, DNP, MPA; Nanibaa' Garrison, PhD; Katrina Claw, PhD Moderator: Vanessa Hiratsuka, PhD
2:15 - 2:45 pm	Q&A with Audience and Panel
2:45 - 3:00 pm	BREAK (15 minutes)
3:00 – 3:45 pm	<u>Panel 4: To Catch a Killer: Law Enforcement Uses of DNA Databases</u> Panelists: James Hazel, JD, PhD; Jennifer Wagner, JD, PhD; Christi Guerrini, JD, MPH; Moderator: Amy McGuire, JD, PhD
3:45 – 4:15 pm	Q&A with Audience and Panel
4:15 - 4:30 pm	Closing Remarks: Sandra Soo-Jin Lee, PhD and Mildred Cho, PhD

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Presenters and Moderators

- **Paul Appelbaum, MD** Elizabeth K. Dollard Professor of Psychiatry, Medicine, and Law, and Director, Center for Law, Ethics, & Psychiatry, Department of Psychiatry, Columbia University.
- **Mildred Cho, PhD** Professor of Pediatrics and Associate Director, Stanford Center for Biomedical Ethics, Stanford University.
- **Katrina Claw, PhD** Assistant Professor, Division of Biomedical Informatics and Personalized Medicine, University of Colorado, Anschutz.
- **Elizabeth Cohn, RN, PhD** Rudin Professor of Nursing and Interim Associate Dean for Research, Hunter College at The Graduate Center, CUNY.
- **Dalton Conley, PhD** Henry Putnam University Professor in Sociology, Princeton University.
- **George Daley, MD, PhD** Dean and Caroline Shields Walker Professor of Medicine, Harvard Medical School.
- **Alecia M. Fair, DrPH** Research Assistant Professor of Medicine, Meharry-Vanderbilt Alliance, Vanderbilt University Medical Center.
- **Rosemarie Garland-Thomson, PhD** Professor of English and Bioethics and Co-Director of the Disability Studies Initiative at Emory University.
- **Nanibaa' Garrison, PhD** Associate Professor, Institute for Society and Genetics, University of California, Los Angeles.
- **Eric Green, MD, PhD** Director of the National Human Genome Research Institute at the U.S. National Institutes of Health.
- **Christi Guerrini, JD, MPH** Assistant Professor, Center for Medical Ethics and Health Policy, Baylor College of Medicine.
- **James Hazel, JD, PhD** Postdoctoral Fellow, Center for Genetic Privacy and Identity in Community Settings, Vanderbilt University Medical Center.
- **Vanessa Hiratsuka, PhD** Research Professional, Center for Human Development, University of Alaska, Anchorage.
- **Steven Hyman, MD** Distinguished Service Professor of Stem Cell and Regenerative Biology, Harvard University.
- **Josephine Johnston, PhD** Director of Research, Research Scholar at The Hastings Center.
- **Eric Juengst, PhD** Director, Center for Bioethics, and Professor, Department of Social Medicine, University of North Carolina, Chapel Hill.
- **Bartha Knoppers, PhD** Canada Research Chair in Law and Medicine and Director, the Centre of Genomics and Policy, Faculty of Medicine at McGill University.
- **Sandra Soo-Jin Lee, PhD** Chief, Division of Ethics, Department of Medical Humanities and Ethics, Columbia University.
- **Natalie Lira, PhD** Assistant Professor, Department of Latina/Latino Studies, University of Illinois, Urbana-Champaign.
- **David Magnus, PhD** Thomas A. Raffin Professor of Medicine and Biomedical Ethics and Director, Stanford Center for Biomedical Ethics, Stanford University.
- **Chief Lynn Malerba, DNP, MPA** 18th Chief of the Mohegan Tribe, Chair, Tribal Self-Governance Advisory Committee of the Federal Indian Health Service.
- **Amy McGuire, JD, PhD** Leon Jaworski Professor of Biomedical Ethics and Director, Center for Medical Ethics & Health Policy, Baylor College of Medicine.
- **Michelle Meyer, JD, PhD** Assistant Professor and Associate Director, Research Ethics, Center for Translational Bioethics & Health Care Policy, Geisinger.
- **Ariadne Nichol, BA** Researcher at the Stanford Center for Biomedical Ethics.
- **Nicole Novak, PhD** Assistant Research Scientist in Community and Behavioral Health, University of Iowa College of Public Health.
- **Pilar Ossorio, JD, PhD** Professor of Law and Bioethics, University of Wisconsin-Madison and Ethics Program Lead at the Morgridge Institute for Research.
- **Pamela Sankar, PhD** Associate Professor, Department of Medical Ethics and Health Policy, University of Pennsylvania.
- **Alexandra Minna Stern, PhD** Carroll Smith-Rosenberg Collegiate Professor of History, American Culture and Women's Studies and Director of the Sterilization and Social Justice Lab, University of Michigan.
- **Elyse Thulin, MS** Doctoral Candidate, Department of Health Behavior & Health Education, University of Michigan.
- **Jennifer Wagner, JD, PhD** Associate Director, Bioethics Research and Assistant Professor, Center for Translational Bioethics & Health Care Policy, Geisinger.
- **Karriem Watson, DHSc, MS, MPH** Director, Office of Community Engaged Research & Implementation Science and Research Scientist, Cancer Center, University of Illinois.
- **Consuelo Wilkins, MD, MSCI** Executive Director, Meharry-Vanderbilt Alliance; Vice President for Health Equity, Vanderbilt University School of Medicine.

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ELSI Congress and ELSI Virtual Forum Organizing Committee

- **Paul Appelbaum** (Columbia University)
- **Jonathan Berg** (University of North Carolina, Chapel Hill)
- **Joy Boyer** (NHGRI)
- **Larry Brody** (NHGRI)
- **Mildred Cho** (Stanford University)
- **Gail Henderson** (University of North Carolina, Chapel Hill)
- **Vanessa Hiratsuka** (University of Alaska, Anchorage)
- **Steven Joffe** (University of Pennsylvania)
- **Dave Kaufman** (NHGRI)
- **Gabriel Lazaro-Munoz** (Baylor College of Medicine)
- **Sandra Soo-Jin Lee** (Columbia University)
- **Nicole Lockhart** (NHGRI)
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- **Lisa Parker** (University of Pittsburgh)
- **Natalie Pino** (NHGRI)
- **James Tabery** (University of Utah)
- **Wendy Uhlmann** (University of Michigan)

THANK YOU!

We hope you found it an enjoyable and valuable experience.

Please help to **organize the next ELSI Congress** by completing the **Evaluation Survey** that will be emailed to all registrants following the Forum.

*The ELSI Virtual Forum is organized and supported by the
Columbia University Division of Ethics,
Stanford University, and the
National Human Genome Research Institute*