



ELSI FRIDAY FORUM

ELSI Friday Forum

Friday, January 10, 2025 12-1:30 PM ET US/9-10:30 AM PT

Session Title:

Public-Private Partnerships for Gene Therapies: What Does the Public Get?

Date and time: Friday, January 10, 2025 | 12pm ET US / 9am PT US

Moderator: P.J. Brooks, PhD

Presenter: John Conley, JD, PhD

Presenter: Eva Winkler, Prof Dr.med., Dr.phil.

CERA Coordinator: Josephine Johnston, LLB, MBHL

Staff: [Ashlin Amano](#), [David Lamb](#), [Faryn Fairweather](#), [Grace Morris](#)

[BIOGRAPHIES]

Moderator: P.J. Brooks, PhD

Philip J. (P.J.) Brooks, Ph.D., is the deputy director of NCATS' Division of Rare Diseases Research Innovation. Brooks represents NCATS in the NIH-wide Gene Therapy Working Group, the Regenerative Medicine Innovation Project and the International Rare Diseases Research Consortium (IRDiRC). He also is the working group co-coordinator for the NIH Common Fund program on Somatic Cell Genome Editing, one of the leaders of the Platform Vector Gene Therapy (PaVe-GT) pilot project and the co-chair of the Bespoke Gene Therapy Consortium.

Link to P.J.'s full biography: <https://ncats.nih.gov/about/our-staff/pjbrooks>

Panelist: John Conley, JD, PhD

John M. Conley is William Rand Kenan, Jr. Professor at the UNC School of Law. He received his law degree and Ph.D. (Anthropology) from Duke, where he was editor-in-chief of the *Duke Law Journal*. After practicing in Boston and Charlotte, he joined the UNC law faculty in 1983. He teaches several courses involving the intersection of science and the law. Conley's research interests include the anthropological study of institutions and organizations, including law firms, investment organizations, corporations, and scientific enterprises, and the application of intellectual property law to emerging technologies. His current research project, conducted in



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collaboration with UNC's Center for Bioethics, is examining the governance of new gene editing technologies.

Link to John's full biography: <https://law.unc.edu/people/john-m-conley/>

Panelist: Eva Winkler, Prof Dr.med.,Dr.phil.

Eva Winkler is an oncologist and Professor for Translational Medical Ethics (previously Heisenberg-Professorship) at Heidelberg University. She heads the Section for Translational Medical Ethics. The section covers the entire range of ethical questions relating to the translation of research results into healthcare. Professor Winkler is a specialist in haematology/oncology and works as a senior physician in the Department of Medical Oncology at the UKHD.

Link to Eva's full biography:

<https://www.nct-heidelberg.de/en/the-nct/organization/directorate/prof-dr-dr-eva-winkler.html>

[FROM CERA]

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This session's featured ELSIhub Collection:

Please use the link to access "Patenting and Licensing in Genomics: Impact on Access to Genetic Tests and Debates about Patenting in the Public Interest."

<https://elsihub.org/collection/patenting-and-licensing-genomics-impact-access-genetic-tests-and-debates-about-patenting> curated by Ellie Park, Student Undergraduate Research Fellow, Arizona State University; Robert Cook-Deegan, MD, Professor, Arizona State University; & Arti Rai, JD, Elvin R. Latty Professor of Law, Duke University School of Law, with input and suggestions from Geertrui van Overwalle, Jacob S. Sherkow, Kathy Liddell, Osmat Azzam, Sean Tu, Joshua Sarnoff, Jorge Contreras, Lisa Larrimore Ouellette, Aaron S. Kesselheim, Shobita Parthasarathy, and Kevin Noonan.

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