CONFÉRENCE

GENETICS, PRIVACY AND LITERATURE

03 mai 2017
Centre Assas, Salle 214

Law & Humanities Workshop : "Genetics, Privacy and Literature"

The conference **"Genetics, Privacy and Literature"** will be held on **Wednesday 3rd May, at 6pm in room 214** of the Assas building of Université Panthéon-Assas.

For its last workshop of the semester, **CERSA**, **Law and Humanities,** and the **Pôle langues** of Université Panthéon-Assas are delighted to welcome **Ellen Clayton**, Professor of Law and Craig-Weaver Professor of Pediatrics, Vanderbilt School and **Jay Clayton**, William R. Kenan, Jr. Professor, Department of English and Director of the Curb Center for Art, Enterprise, and Public Policy.

The conference programme is the following :

> **Ellen Clayton: "Privacy in our Genomic Future - A View from the US" (commentator: Jennifer Merchant, Université Panthéon-Assas)**
> **Jay Clayton: "Data in Dystopia: The End of Privacy in Contemporary Literature and Film" (commentator: Yvonne-Marie Rogez, Université Panthéon-Assas)**

E-mail registration is required for people who are not members of CERSA or of Université Panthéon-Assas (staff and students).

Ellen Wright Clayton is an internationally respected leader in the field of law and genetics who holds appointments in both the law and medical schools at Vanderbilt as well as 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. 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 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 currently co-chair of the National Academies' Report Review Committee. She is an elected Fellow of the American Academy for the Advancement of Science.

Selected Bibliography

"Why the Americans with Disabilities Act Matters for Genetics," 313 *Journal of the American Medical Association* 2225 (2015).
"How much control do children and adolescents have over genomic testing, parental access to their results, and parental communication of those results to others?" *Journal of Law, Medicine, and Ethics* (2016).
"Can I Be Sued for That ? Liability Risk and the Disclosure of Clinically Significant Genetic Research Findings," 24 *Genome Research* 719 (2014) (with Amy L. McGuire, Bartha M. Knoppers and Ma'n H. Zawati).
"What Should the Law Say About Disclosure of Genetic Information to Relatives," 1 *Journal of Health Care Law & Policy* 373 (1998).

Jay Clayton is author or editor of seven books and more than 35 articles and chapters, and he has received fellowships from the Guggenheim Foundation, the American Council of Learned Societies, and elsewhere. His published scholarship has ranged from Romantic poetry and the Victorian novel to contemporary American literature, film and digital media, science and literature, and medicine, health, and society. His book, *Charles Dickens in Cyberspace: The Afterlife of the Nineteenth Century in Postmodern Culture*, focused on the depiction of computers, information technology, and cyborgs from the Victorian era to the twenty-first century. This study won the Suzanne M. Glasscock Humanities Prize for Interdisciplinary Scholarship. His recent work has concentrated on the ethical, social, and cultural issues raised by genomics.

Selected Bibliography

"*The Ridicule of Time: Science Fiction, Bioethics, and the Posthuman*" , (American Literary History 2013).
Charles Dickens in Cyberspace: The Afterlife of the Nineteenth Century in Postmodern Culture (Oxford University Press, 2003).
The Pleasures of Babel: Contemporary American Literature and Theory (Oxford University Press, 1993)
Romantic Vision and the Novel (Cambridge University Press, 1987).

Affiche

GENETICS, PRIVACY AND LITERATURE

Wednesday 3rd May 6pm-8pm, room 214
Université Panthéon-Assas (Assas building)

A ***Law & Humanities Workshop*** moderated by:
Jennifer Merchant & Yvonne-Marie Rogez

with

Ellen Clayton

Professor of Law and
Craig-Weaver Professor of Pediatrics,
Vanderbilt Law School

"Privacy in Our Genomic Future - A View from the US"

and

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Director of the Curb Center for Art,
Enterprise, and Public Policy

"Data in Dystopia: The End of Privacy in Contemporary Literature and Film"

Courriel : law&humanities@u-paris2.fr
Twitter : @LawHumanities
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