

Bioethicists use theatrical narratives to bridge the gap between society and science

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A pair of bioethics experts have added "playwright" to their resumes in an effort to aid the genomics community in grappling with an onslaught of ethical issues as genomic science transitions to bedside healthcare, a decade after the human genome was first sequenced.

Until now the plays of Karen H. Rothenberg and Lynn W. Bush have been performed for, and by, their peers and others in the genomics community at global conferences, meetings and in classrooms. With Oxford University Press' publication of the book *The Drama of DNA: Narrative Genomics*, excerpts from the plays, along with analysis and discussion of the ethical and cultural issues surrounding genomic science and medicine, are available to a wider audience. A companion website to the book provides links to Bush and Rothenberg's plays in their entirety.

"Drama and the fictionalization of societal issues have always aided us in grappling with the issues of the day, and the discord that can arise where a new technology and culture first meet," says Rothenberg, a faculty member at the Johns Hopkins Berman Institute of Bioethics and the Marjorie Cook Professor of Law at the University of Maryland Francis King Carey School of Law. Rothenberg also currently serves as Senior Advisor to the Director on Genomics and Society, National Human Genome Research Institute, National Institutes of Health (NHGRI/NIH).

In the first chapter, titled "Why Genomics, Why Narratives, Why Now?" Rothenberg and Bush write, "Many challenges surround the promise of genomic technology and the power of genomic information, as they alter



conceptions of identity and dynamics within personal, familial, and professional relationships. Controversial issues abound—such as determining whether, what, to whom, when, and how genomic information should be disclosed to individuals and their families—and whose voices matter in making these determinations."

Eric D. Green, Director of NHGRI and an experienced "actor" in Rothenberg and Bush's plays, writes in the book's foreword, "Effectively examining the implications of genomic advances requires interdisciplinary collaborations. Toward that end, narrative genomics developed by Karen Rothenberg and Lynn Bush offers a novel path to enhance the understanding and dialogue among clinical geneticists, genetic counselors, bench scientists, primary care physicians, bioethicists, policy makers, other researchers and healthcare professionals, patients, and patient advocates."

Professor Nancy E. Kass has also had the opportunity to take on an acting role in Rothenberg and Bush's plays, and agrees with Green on the value of the dramatic approach to educating on ethical issues. "Professionals always appreciate a more creative way to communicate ideas than being 'talked at'. These plays and scripts allow fun and interactive discussion of tough ideas in ways that appeal to patients and professionals alike," says Kass, the Phoebe R. Berman Professor of Bioethics and Public Health at the Berman Institute.

Rothenberg first began writing with Bush, a faculty member in Pediatric Clinical Genetics and faculty associate at the Center for Bioethics at Columbia University Medical Center, after the two attended an interdisciplinary seminar on narrative medicine at Columbia. Both wanted to enhance dialogue and understanding about the complex societal challenges raised by generating and sharing vast amounts of genomic information.



In addition to original plays, Rothenberg and Bush have collaborated on historical research on plays exploring bioethics issues; in 2012 the scholars published an article in the *Houston Journal of Health Law & Policy* surveying 46 plays spanning three centuries—including *Frankenstein* and *Who's Afraid of Virginia Woolf?*—all highlighting the ethical and social impact of medical technology on society.

Expanding on the themes of interdisciplinary dialogue, this spring Rothenberg organized a workshop at NIH that brought playwrights and NHGRI scientists together to discuss both fictional and real-life drama in the world of science, followed by a public event at the Smithsonian National Museum of Natural History, in which playwrights shared how genomics has influenced their work.

Next, Rothenberg and Bush's work will be shared in an interactive format with the staff of the Presidential Commission for the Study of Bioethical Issues and at Harvard Medical School. Rothenberg says she looks forward to expanding the workshop format and enhancing dialogue between playwrights, scientists, bioethicists and others in the genomics community in this novel context.

More information: The Drama of DNA: Narrative Genomics, Amazon.com: www.amazon.com/Drama-DNA-Narra ... eywords=drama+of+dna

Karen H. Rothenberg <u>www.bioethicsinstitute.org/peo ... e/karen-h-rothenberg</u>

Lynn W. Bush: www.cumc.columbia.edu/dept/bec/staff/LynnBush.html

Provided by Johns Hopkins University School of Medicine



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