



# NEWS

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## **“Drama of DNA” will explore “incidental” findings and other challenges of whole genome sequencing of children and adults**

A provocative new interactive play, “The Drama of DNA: Anticipating the Future with WGS,” will be performed by a cast of distinguished genomics professionals on the first evening, Tuesday, Oct. 22, of the American Society of Human Genetics annual meeting in Boston.

Fictionalized characters will explore a hypothetical research protocol in which the entire DNA codes of children diagnosed with autism spectrum disorder (ASD), their “unaffected” siblings and parents, including their pregnant mothers, will be deciphered. The play will bring to life the challenges and potential implications of using whole genome sequencing (WGS) in research and medicine, said the co-authors, Lynn W. Bush, Ph.D., and H. Rothenberg, J.D., M.P.A.

Dr. Bush, a psychologist and bioethicist, is a member of the faculty of pediatric clinical genetics at Columbia University. Rothenberg, the founding director of the Law and Health Care program at the University of Maryland School of Law, is senior advisor on genomics and society to the National Human Genome Research (NHGRI) Director Eric D. Green, M.D., Ph.D., one of the play’s 13 “actors.”

Among the other genomics professionals who will participate in the play are: James P. Evans, M.D., Ph.D., Bryson Distinguished Professor of Genetics and Medicine, University of North Carolina, Chapel Hill; Stephanie Malia Fullerton, D.Phil., Associate Professor of Bioethics and Humanities, University of Washington School of Medicine; and Robert Nussbaum, M.D., Professor, Department of Medicine, and Chief, Division of Medical Genetics, UCSF.

“The Drama of DNA” is a creative approach to enhance professional understanding and stimulate interdisciplinary discourse on the ethical, social and psychological issues raised by WGS, according to the co-authors.

They added that the rapidly declining cost of WGS has increased exponentially the demand for its clinical applications and the ethical challenges facing health professionals, individuals, families and society, said the co-authors. Because the field is still evolving, these challenges are even more complex since so much uncertainty exists about the probability that a gene or genetic trait will be expressed.

“Communicating genomic findings of unknown significance, suggestive of disease or a stigmatizing disorder to healthy individuals must be carefully weighed against benefits, especially when involving children,” said Dr. Bush.

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Genomic technologies can uncover “potent information that extends beyond the individuals whose whole genomes are being sequenced to include blood relatives and ancestral groups,” added Rothenberg.

For example, the results of WGS of an unaffected brother or sister of a child with a severe chronic disease may reveal that the sibling has a genetic predisposition for another disorder, such as a life-threatening heart problem. Or, WGS may indicate that the DNA of the fetus of the child’s pregnant mother has one or more of the genes that increases risk for developing ASD or another condition.

“Such genomic ‘incidental’ findings can be emotionally unsettling, particularly when neither families nor professionals fully anticipate the range of findings that could be discovered by WGS as well as the impact of that information on individuals,” said Dr. Bush.

Some consent documents signed prior to WGS allow individuals to decline receiving information about incidental findings. “But, there is little consensus regarding under what circumstances, if any, an individual’s or family’s request ‘not to know’ may or may not be honored,” said Rothenberg.

Between each of the three acts of the play, Dr. Bush and Rothenberg and the “actors” will engage the audience in discussions about the ethical, psychosocial and policy issues that have been raised.

“This year’s scientific program illustrates the increasing power, accessibility and importance of whole genome sequencing in the clinical setting, and many of our members have been instrumental in the development and application of the technology,” said ASHG Executive Vice President Joseph D. McInerney.

“This play explores the myriad implications of WGS for individuals and society and is certain to elicit great interest from our membership and strong participation from those in the audience,” McInerney added.

“The Drama of DNA” and other plays co-authored by Dr. Bush and Rothenberg have been adapted for a book to be published by Oxford University Press.

### **About ASHG**

The American Society of Human Genetics is the primary professional membership organization for nearly 8,000 human genetics specialists worldwide. The ASHG Annual Meeting is the world’s largest gathering of human genetics professionals and a forum for renowned experts in the field. For more information about ASHG, visit: <http://www.ashg.org>.