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Symposium – From Bench to Society: Law and Ethics at the Frontier of Genomic Technology

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Symposium Articles

From Bench to Society: Law and Ethics at the Frontier of Genomic Technology

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On February 8, 2013, the UCSF/UC Hastings Consortium on Law, Science, and Health Policy and the *Hastings Law Journal* co-sponsored a symposium titled *From Bench to Society: Law and Ethics at the Frontier of Genomic Technology*. The impetus behind this conference was to bring together leading national scholars trained in genetics, genetic counseling, medicine, law, philosophy, psychology, sociology, ethics, and public policy to spend the day examining the vast potential implications (both good and bad) of the next wave of major advances in genetic and genomic testing for patients, providers, their families, the practice of medicine, and society as a whole. We hoped to inspire the group to think collectively about what we can do now to glean all of the potential benefits we can from spectacular scientific achievements, such as whole genome sequencing, whole exome sequencing, and epigenetics, while simultaneously implementing safeguards to protect individuals and society from the challenges that lay ahead. The day was quite eye-opening for audience members and panelists alike, and fostered numerous discussions and potential collaboration opportunities during breaks and the end of the day reception.

The day began with an introduction to genetics and genomics by Professor Kelly Ormond, who provided the non-scientists in the room with a wonderful overview of everything from the basics of genetic science to recent developments in sequencing and targeted sequencing analysis. Professor Ormond's presentation set the stage for subsequent discussions.

We then moved into our first of three substantive panels, titled

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Predictions of Future Health, which I moderated. This panel posed significant questions regarding the potential benefits and detriments of using whole genome sequencing to make predictions of future health states. Dr. Wylie Burke focused her presentation on the expansive set of information available through whole genome sequencing and the challenges of communicating that information to individuals. She also argued, as do she and her colleagues Susan Brown Trinidad and Ellen Wright Clayton in their Article in this issue, *Seeking Genomic Knowledge: The Case for Clinical Restraint*, that health care providers should only focus on genetic information that has sufficient clinical utility to guide medical decisions. This proposal would open the door to private companies that offer personal genetic information directly to consumers regarding a large portion of the human genome that so far reveals little actionable clinical information. Next, Dr. Mildred Cho presented evidence on how the implementation of genomics in clinical practice is being driven by forces other than the clinical judgment of clinicians. Further, her presentation explored the role that insurance, lack of comprehensive regulatory policy, commercialization, and particularly, intellectual property policy play in determining the use of genomic advances. Finally, Professor Mark Rothstein acknowledged that for symptomatic or high risk individuals, whole genome sequencing is a marvelous advance in diagnostic testing. He then argued his lecture titled *The Case Against Precipitous, Population-Wide Whole Genome Sequencing*, which explored the significant challenges associated with whole genome sequencing for asymptomatic individuals, including a lack of clinical utility, lack of available genetic counselors to help translate the data to patients, and a general lack of societal understanding of the implications of many genetic findings. This panel raised many questions regarding what information should be returned to individuals as a result of genetic sequencing. Many of these issues are addressed in the Article *Return of Results in Genetic Testing: Who Owes What to Whom, When and Why?* by Stephanie Alessi.

After lunch, Dr. George Poste gave the keynote address titled *Personalized (Precision) Medicine: Science, Law and Health Policy.* Dr. Poste's presentation provided a whirlwind view of the technological potential to offer precision medical care designed for individual patients, including the use of personal handheld mobile devices to gather and communicate health data to providers on a regular basis. He also noted the significant privacy, economic, regulatory, and translational challenges that access to both genomic information and the technological capability to provide that information to individuals will create. Dr. Poste's keynote spurred many questions and much discussion regarding how best to address patient demand and offer clinically relevant information.

Following the keynote address, Professor Osagie Obasogie moderated our second substantive panel titled *Individualized Medicine*. Dr. Robert Nussbaum discussed the scientific and clinical challenges that exist in today's relatively unregulated and privatized world of genetic and genomic research. Like Dr. Cho, he noted that the commercialization of clinical research and treatment has led to substantial inefficiencies in the system, including an inability to identify prior cases of rare genetic diseases. He argued for improved regulation of genetic tests and greater public access to genetic data. Next, Dr. Barbara Koenig gave a very interesting presentation from the perspective of an anthropologist examining the growth of the commercial genomic industry in the last few years, and the societal forces that have contributed to that growth. She argued that critical examination of genomics and its role in society is needed to properly address the societal changes that access to this technology portends. Finally, Professor Hank Greely examined the wide range of challenges that arise with personalized genomics, specifically the challenge associated with creating computer programs to analyze the genome and translate the sequence into meaningful information for patients. Professor Greely proposed the creation of an entity to continuously and simultaneously curate the medical literature and interpret both genetic variations to disease risk and the strength of the findings. This information could then be published on the Internet, subject to peer review and open comment. Such a tool could be used to continually update all clinicians and researchers with information on the relevance of certain genotypes.

Our final panel of the day, moderated by Professor David Faigman, examined recent advances in behavioral genetics and its potential for use in legal settings. This panel was conducted in a Fred Friendly format, which gave all of our panelists, Professor Josh Buckholtz, Professor Deborah Denno, Professor Nita Farahany, and Dr. Taylor Smith the opportunity to answer all questions posed by Professor Faigman and the audience. This panel was the most lively of the day, and Professors Buckholtz, Denno, and Farahany engaged in a fascinating debate regarding the usefulness of behavioral genetics research and individual genotypes in criminal sentencing. Describing the use of genetics in criminal courts for mitigation purposes, Professor Farahany noted that it had not been very compelling. Professor Denno argued in favor of permitting genetics information that has been associated with certain behaviors to be used in death penalty sentencing. Her article in this issue critiques a study recently published in *Science* by Aspinwall, Brown, and Tabery titled *The Double-Edged Sword: Does Biomechanism Increase or Decrease Judges' Sentencing of Psychopaths?* Further, Dr. Smith discussed the role of epigenetics in psychological and behavioral

disorders, and he and his coauthors, Matthew Maccani and Valerie Knopik, explore the use of epigenetic research in a legal and policy context in their Article in this issue titled *Maternal Smoking During Pregnancy and Offspring Health Outcomes: The Role of Epigenetic Research in Informing Legal Policy and Practice*.

Overall, the day proved fascinating though daunting on many fronts. I invite you to view the conference on the UCSF/UC Hastings consortium webpage, as this brief introduction cannot begin to do it justice. The opportunities that we, as a society, will have to explore our genetic information, to have a better understanding of the role our genetics plays in the development of disease, and in some cases, behavior are unbounded. However, significant challenges will arise regarding how we analyze, translate, understand, and protect this information. A general consensus appeared to exist that genomic technology is coming at a pace that far exceeds our ability to address these challenges and that as a society, we are largely unprepared for its arrival. However, through interdisciplinary symposia like this one, we can improve our understanding of the implications of advances in genomics and ignite further discussions and collaborations on how to best handle the individual and societal risks associated with some of our greatest scientific achievements.