

T13.3

**Challenges of Biomedical Ethics in Modern Medicine:
From Training to Practice**

13:15 Theatre 1

Am I My Genes?: Challenges in Understanding and Incorporating Genetics into Healthcare*Klitzman R**Psychiatry Department, Columbia University, USA*

Genetic testing is rapidly advancing, improving the diagnosis and treatment of numerous diseases, including breast and other cancers, cystic fibrosis, Alzheimer's and Huntingtons. But physicians, other healthcare providers, patients, family members, policy makers and others often face challenges in understanding and knowing how to incorporate genetic information into healthcare. These challenges are growing with the rapid development and use of whole genome and whole exome sequencing, and testing of embryos through Pre-implantation Genetic Diagnosis of fetuses through Non-Invasive Prenatal Diagnosis. This presentation will explore these challenges and questions, and share how providers, hospitals and healthcare systems and patients can best respond.

Patients confront a series of quandaries – for instance, whether to be tested, for which conditions; whether to disclose their genetic risks to parents, siblings, spouses, offspring, friends, doctors, insurers, employers, and schools; how to view and understand themselves and their genetics; what treatments, if any, to pursue; whether, if they are at risk of having a serious mutation, to have children, adopt, screen embryos, or abort; and whether to participate in genetic communities. They struggle to understand these tests and probabilities, and avoid fatalism, anxiety, despair, and discrimination. Studies show that providers are often unsure how to address these issues with patients, and feel they need more training in when to order and how to interpret tests. Healthcare systems face dilemmas about creating biobanks – when to do so, what information should be included, who should have access to these data, and how concerned to be about possible breaches of confidentiality. New technologies pose dilemmas as well – e.g., when gene editing through CRISPR-Cas9 or other technologies should be used.

Underlying ethical dilemmas emerge through these related realms – what risks and benefits are involved, what rights patients have, and how to ensure that the benefits of genetics are available to all members of society. This presentation will examine these issues and how they can be best addressed.