

### Genetics, Ethics and the Law

Human genetics is a rapidly evolving field in medicine. While the field holds great promise, it also creates special legal and ethical issues. This course will explore the legal and bioethical implications of genetic practice and research from American and international perspectives. Topics of discussion will include the application of ethical concepts in genetics ('Genethics'); the nature of informed consent concerning genetic testing and genetic research, confidentiality and the duty to warn about genetic-related conditions; liability and risk management to avoid malpractice; individual and group privacy interests concerning identifiable genetic data; ethical analysis of public health initiatives (genetic screening, national repositories); insurance and employment discrimination based on genetic predispositions; sex selection; genetic and intellectual property issues, and a survey of cutting-edge genomic research.

Organizing Committee: R. Bonnie, M. Riley, G. Siegal,<sup>1</sup> L. Silverman (UVA)  
N. Callanan, S. Schmerler

*All Sessions in WB104 unless otherwise indicated*

#### **DAY 1 (Friday, May 29, 2009)**

##### **Morning Session - Introduction**

- 11:00 – 11:15** General introduction to the course (Deans, Organizing Committee)
- 11:15 – 12:00** Keynote Speaker – James F. Childress (UVA)  
*Basic concepts in modern bioethics*
- 12:00 – 12:45** 'Gene-ethics' – *Applying bioethical concepts to genetics and genomics*  
Lois Shepherd (UVA)
- 12:45 – 1:45** Working Lunch break & workshops – case discussion: *Genetic testing and adoption* (Moderators – Course's faculty) (WB127 - lunch; WB121, WB129)

##### **Afternoon Session – Patients and their Families**

- 2:00 – 2:45** *Patients' Rights – Consent, confidentiality* – Sonia M. Suter (GWU)
- 2:45 – 3:30** *Genetic information and the right to know/not to know; Genetic information and family's rights* – Madaline Harrison (UVA)
- 3:30 - 4:00** Break (WB127)
- 4:00 – 5:00** Keynote Speaker – Mark Rothstein (Louisville)  
*Post GINA – Genetic information and the insurance/employment arenas*
- 5:00 – 5:30** Discussion

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## DAY 2 (Saturday, May 30, 2009)

### Morning Session – Public Health and Screening Policies

- 8:30 - 9:00 Continental Breakfast (WB127)
- 9:00 – 9:20 *Introduction to ethics and law in public health genetics - Ruth Gaare-Bernheim (UVA)*
- 9:20 – 10:00 *Managing genetic samples and information – access, security and privacy*  
Mark Rothstein (Louisville)
- 10:00 – 10:30 *Legal and ethical challenges of genetic testing and screening (A)-*  
Margaret Riley (UVA)
- 10:30 - 11:00 Break (WB127)
- 11:00 – 11:45 *Legal and ethical challenges of genetic testing and screening (B) –Carriers, pre marital, chronic diseases - Sonia M. Suter (GWU)*
- 11:45 – 12:30 *Another look at free markets – regulating genetic tests - Larry Silverman (UVA)*
- 12:45 – 1:45 Working Lunch break & workshops: Non-medical sex selection  
(Moderators – Course’s faculty) (WB127 - lunch; WB121, WB129)

### Afternoon Session—Genetic Research

- 2:00 – 2:45 *Genetic research – the ethical and legal framework - special issues in genetics research –Myra Roche (UNC)*
- 2:45 – 3:30 *Pharmacogenomic research – Mark Rothstein (Louisville)*
- 3:30 - 4:00 Break (WB127)
- 4:00 – 4:40 *What is happening in Genetic and genomic research - Josyf Mychalecki (UVA)*
- 4:40 – 5:30 *Personalized medicine, Direct to Consumer Marketing and the FDA—Margaret Riley (UVA)*

## DAY 3 (Sunday, May 31, 2009)

### Morning Session – Genetic Research—Intellectual Property Issues

- 8:30 - 9:00 Continental Breakfast (WB127)
- 9:00 – 9:45 *Introduction to intellectual property –Margo Bagley (UVA)*
- 9:45 – 10:30 *Intellectual property in Genetics - Becky Anderson (U. of Nebraska)*
- 10:30-11:00 Break (WB127)
- 11:00 – 11:45 *Biobanks – comparative ethico-legal analysis - Gil Siegal (UVA)*
- 11:45 – 12:30 *Pipeline Pharmacogenetics - changing the industry from the inside–*  
Iris Grossman, (Cabernet Pharmaceuticals)

**12:45 – 1:45 Working Lunch break & workshops: Direct to consumer genetic testing (Moderators – Course’s faculty) (WB127 - lunch; WB121, WB129)**

**Afternoon Session – Liability Issues**

**2:00 – 2:45 *Genetics and malpractice/negligence* – Introduction - Gil Siegal (UVA)**

**2:45 – 3:30 *Genetics and malpractice/negligence – Standard of care, wrongful life cases, the limits of informed consent in modern genetics* - Susan Schmerler, (St. Joseph’s Children’s Hospital)**

**3:30 - 4:00 Discussion**

**4:00 - 4:40 Concluding session –Keynote speaker – Allen Roses (Shiraz Pharmaceuticals), *ELSI issues for a new AD diagnostic, and a PGX-informed Alzheimer Disease Prevention Drug Trial***

**4:40 Adjourn and awarding certificates**