



The Center for Integration of Research on Genetics and Ethics invites you to:

**CIRGE Seminar**  
**with Amy McGuire, JD, PhD**

**Genomic Data Sharing:  
Ethics, Policy, and  
Participant Perspectives**

**Wednesday, March 17, 2010**

**4 - 5:30PM**

**Munzer Auditorium, Beckman Center**

CIRGE is pleased to welcome Dr. Amy McGuire who is an Associate Professor of Medicine and Medical Ethics as well as the Associate Director of Research at the Center for Medical Ethics and Health Policy, Baylor College of Medicine.

Since the beginning of the Human Genome Project, genomic information generated during the course of research has been viewed primarily as a community resource, with broad data sharing policies adopted for large scale sequencing studies and federally-funded genome-wide association studies (GWAS). Yet, most of these policies were developed with little input from members of the public and in the absence of data on participant perspectives. Dr. McGuire will discuss genomic data sharing policies and will present data on participants' attitudes toward, judgments about, and decisions regarding sharing data in genetic association studies. A randomized study of three different types of consent offering varying levels of control over the decision about data sharing was completed with 330 participants from six genetic-association studies at Baylor College of Medicine. A follow-up survey with 250 participants provides insight into participants' judgments about the risks and benefits of data sharing, broad access to genomic information, and desired information and control over data sharing decisions.

For more information, please visit <http://cirge.stanford.edu/activities/events.html>.