**Why patient consent?**

**Foundational**

- Medical research must never be a prerequisite for access to medical treatment.
- Patients are not guinea pigs.
- Nuremberg Code: “The voluntary consent of the human subject is absolutely essential.”
- Genetic research presents real dangers (discrimination, social status, emotional).
- Genetic research includes activities that may be opposed by the subjects of the research or violate their ethical, moral, cultural or religious values and beliefs.
- DNA cannot be made unidentifiable.

**Laws Inadequate**

- Minnesota government has full access to all medical record data (62J.321).
- State/Federal laws do not protect citizens against unconsented genetic research.
- 18% of Mayo’s patients have unwittingly given “passive authorization” (144.335).

**Informed Consent**

- Genetic research is often not specified on consent forms, or separated as a separate consent decision item.
- Millions of patients have been treated at Mayo — before they even knew about genetic research.
- Most patients do not know that Mayo and other institutions are storing tissues and serums collected in the process of their clinical care.
- Children treated at Mayo grow up and become adults who never gave their consent.

**Bottom Line**

- People are first and foremost human beings, deserving of dignity, respect, and a right to refuse having their bodies and body parts used for medical or genetic research.
- Government-approved unconsented research on human tissues and fluids creates a slippery slope—toward government conscription of bodies and organs for transplantation.
- Medical ethics and patient rights supersede all state business initiatives.
- At stake is the integrity of medical research, patient trust, the patient-doctor relationship, the integrity of the medical profession, and the rights and dignity of patients.