

## 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.