Ethics and Genetics

- Medical Privacy
- Informed Consent
- Adherence to International Standards of Human Rights
- Group versus Individual Rights

Medical Privacy

- A DNA sample can be stored for years
- A DNA sample can be divided and moved between laboratories
- The initial reason for taking the DNA sample may be disassociated from the later use of that sample
- Many people may have access
- Links to actual donor may not be coded

Albinism

- A mutation in the biochemical pathway for the production of melanin pigment
- Inherited as a recessive mutation, since one copy of the wild type enzyme is enough to produce normal levels of pigmentation (haplosufficiency)
- Some human populations have albinos individuals at polymorphic (>5%) frequency (ex: Native Americans of the Hopi tribe)

Hopi
Genetic screening

- Who gives informed consent for minors?
- What kind of experimentation is permissible with children, mentally retarded individuals, the insane, or demented patients?
- IRB’s: institutional review boards and the need to review research protocols for federally funded research (ex: NIH, NSF)
- Committees for the Protection of Human Subjects

What about genealogy searches?

- Mtdna, Ydna

DNA markers in genealogy

- Non maternity is usually not an issue
- Non paternity in urban populations is common
- Estimates of non paternity in USA vary-
  - 40% in Upper East Side Manhattan
  - 20-25% urban Baltimore
  - 5% = national average

This is why some genetics classes no longer do blood typing as a class exercise
Informed Consent

- Participants (patients, research subjects) must be informed of the risks and benefits of the research
- Participants must be competent to appreciate the risks and benefits and to reason about them in light of their own stable value systems
- Minors and incompetent individuals should have competent surrogates who decide on their behalf
- Ethicists cannot agree on whether incompetent adults or minor children should be asked to participate in any research, including family studies, if there is no likely benefit to accrue to them
1. Black urine disease

2. Mendelian recessive

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