Ethics, Eugenics, and Pre-Implantation Genetic Diagnosis
Eugenics

- “Good genes” or “good birth”
- The use of genetics to improve the health of a population
“Our starting point is not the individual, and we do not subscribe to the view that one should feed the hungry, give drink to the thirsty, or clothe the naked ... Our objectives are entirely different: We must have healthy people in order to prevail in the world.”

Joseph Goebbels, Nazi Minister of Propaganda, 1938
LEGISLATIVE STATUS OF EUGENICAL STERILIZATION IN THE UNITED STATES
AND THE TOTAL NUMBER OF OPERATIONS BY EACH STATE TO JANUARY 1, 1935.

Total number of operations to
January 1, 1935 - 21,539

States with Eugenical Sterilization

States with bills pending January 1, 1935.
Laws repealed.

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Win "Fitter Families" Sweepstakes

The Kelley family won by only a narrow margin for the title of "Fitter Family," Mrs. Watts said today. In discussing the award, the Kelley family was not only the highest in the senior division, but they also placed highest in the junior division.

This year was the second that the "Fitter Family" contest has been held. The contest is sponsored by the State Fair of Georgia and is open to all families in the state. The award is given to the family that has shown the most improvement in physical fitness over the course of the year.

Mrs. Watts congratulated the Kelley family on their achievement and noted that the contest is not only a way to encourage families to lead a healthier lifestyle, but also to promote a sense of community and togetherness.

The Kelley family has been participating in the contest for the past two years and has consistently shown improvement in their scores. Mrs. Watts believes that the family's dedication to fitness and their commitment to each other are the key factors that have contributed to their success.

The contest is open to families of all ages and backgrounds, and winners are determined based on factors such as body composition, muscular endurance, and cardiovascular fitness. The Kelley family's win is a testament to the importance of these factors in maintaining a healthy lifestyle.
Eugenics

- Positive eugenics (Francis Galton): Encourage people with “good genes” to have more children
- Negative selection: Don’t allow “bad genes” to be reproduced
  - Forced sterilization or abortion
  - Marriage restrictions
  - “Euthanasia”
The Carrie Buck case
Genetics and Medicine

- Genetic testing
- Prenatal genetic testing
- Pre-implantation genetic diagnosis
- Genetic counseling for prospective parents
Genetic Testing

- Predictive testing: Polycystic kidney disease
- Fluid-filled sacs grow on kidneys, possibly other organs
- Autosomal dominant (50% chance if one parent is affected)
- Onset: 30 to 40 years, possibly earlier/later
- No cure available; life-prolonging treatment possible (dialysis or kidney transplantation)
Genetic Counseling

“An informative and supportive dialogue regarding a known, potential, or unsuspected genetic condition.”

Manic-depressive illness (Kay Redfield Jamison)

“To whom is the genetic counselor responsible? The patient or married couple alone? Other family members? Future generations who may suffer increasing numbers of persons with genetic defects?”

Ruth Macklin, “Moral Issues in Human Genetics: Counseling or Control?”
Cystic fibrosis

- Recessive (25% chance if both parents are carriers)
- Life expectancy: 30 years
- Carrier test available to pregnant couples or those planning to become pregnant
PGD

Pre-implantation genetic diagnosis
PGD

Egg + Sperm
Using IVF techniques

Remove one or two cells for testing

Test DNA or chromosomes

Genetic disorder excluded
embryo implanted

Genetic disorder detected
embryo discarded

test result
Nash Case

- Fanconi Anemia:
  - Recessive (25% offspring affected)
  - Dismorphologies, mildly reduced IQ, leukemia by 6-7 years old, require hematopoietic stem cell transplant (bone marrow) to survive, donor must be HLA (human lymphocyte antigen) matched.
Nash Case

- 6-year-old Molly affected by Fanconi Anemia (FA)
- Nashes hope to have more unaffected children
- Seek 2-stage PGD: FA- & HLA match for Molly
- 5 IVF cycles to get 1 matched embryo
Role-Play Activity

- We are the Ethics Review Board for General Hospital, a local public hospital. The Review Board has to determine a policy for the hospital regarding whether PGD should be permitted for the following purposes:

  - to help two CF carriers avoid passing on the disease;
  - to help a couple produce umbilical cord cells for an existing child with Fanconi’s anemia;
  - to help a couple select the sex of their child for “family balancing”;
  - To help a short couple produce a taller child.