

GENDER, JUSTICE AND THE NEW HUMAN BIOTECHNOLOGIES:

New Challenges for Equality, Human Rights and Social Justice



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Outline



- Bioethics or biopolitics
- Review the technologies
- Concerns raised
- Opportunities

Emerging technologies
are:



- Developing without critical dialogue – no organized social justice, health, and women’s health perspectives
- Market driven – commercialization of science & health
- Developing in a social, political and economic context of inequality and discrimination -- they can replicate or exacerbate inequality

Bioethics or Biopolitics



- **Bioethics:** ethical questions in research, development, experimentation and use of biotechnologies and biomedicine. Origins and focused on individuals in research & clinical context
- **Biopolitics:** the political & public policy implications of the ethical questions in biotechnologies and biomedicine. Focus on broader social impacts, not just impact on individuals.



Bioethics

- Health, safety
- Ethical experimentation
- Doctor/patient relationship
- Individual autonomy & informed consent

- Academics, medical professional, scientists & experts

Biopolitics

- Broader social impacts and context – Power, politics and policy
- Heterogeneous ethical standards that are politically contested

- Civil society participation in decisions making -- political

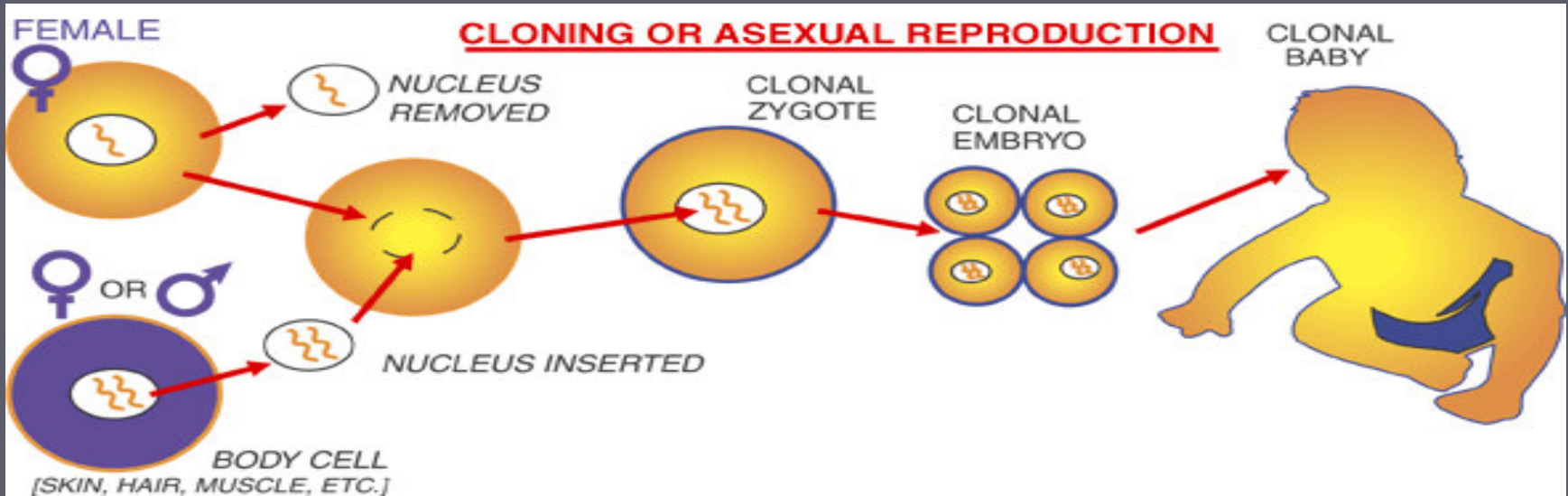
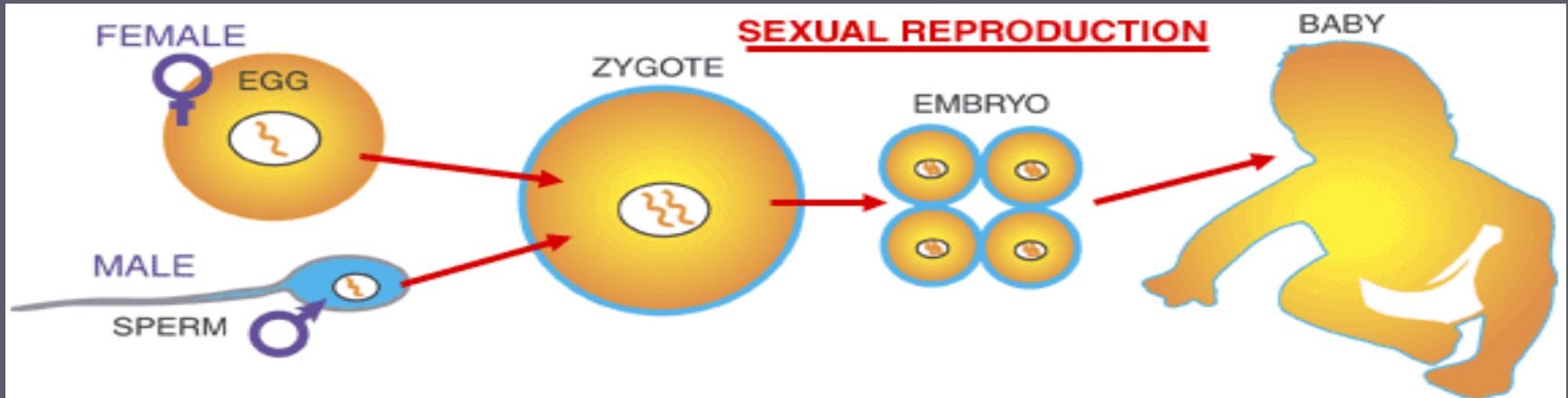
Biopolitical Questions



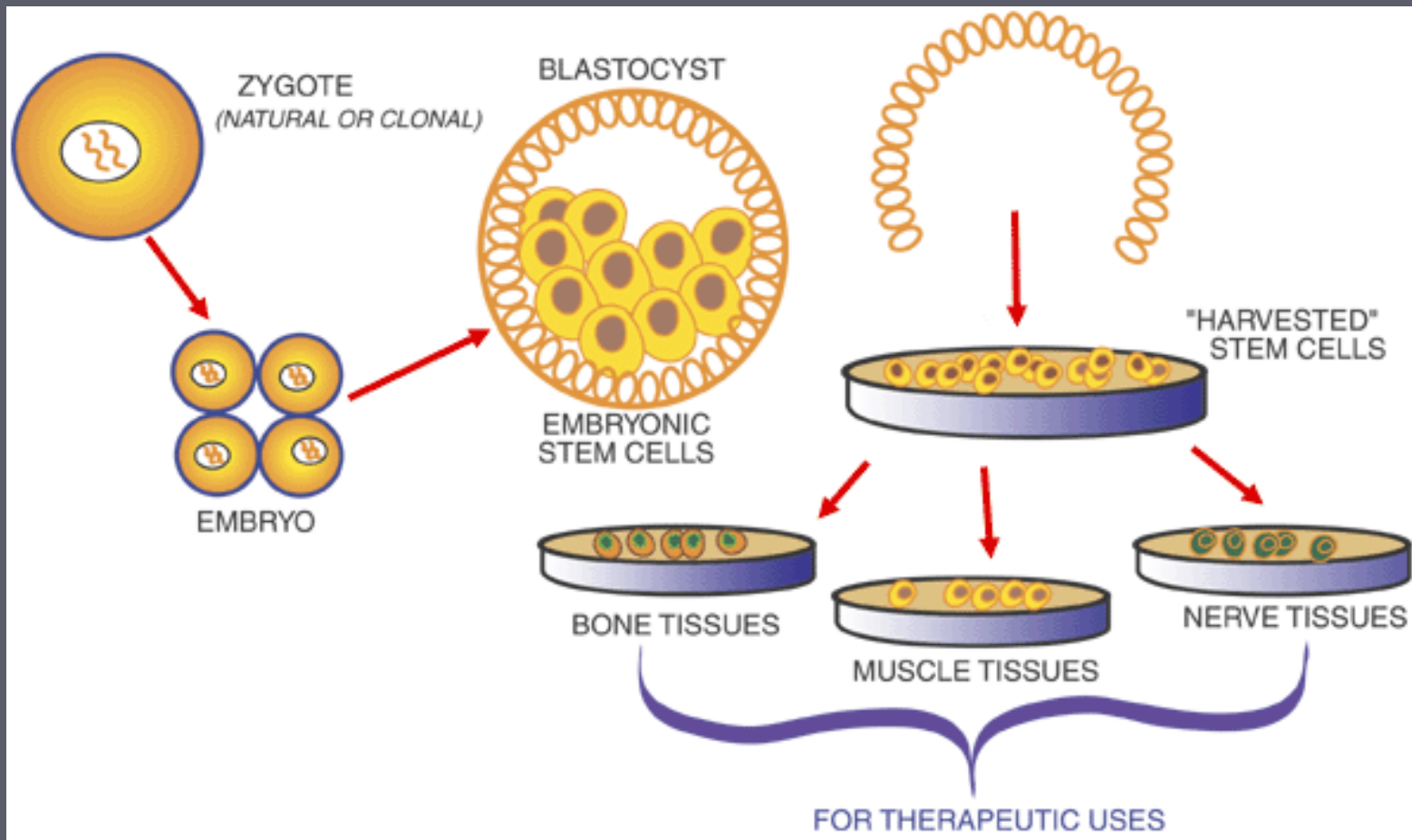
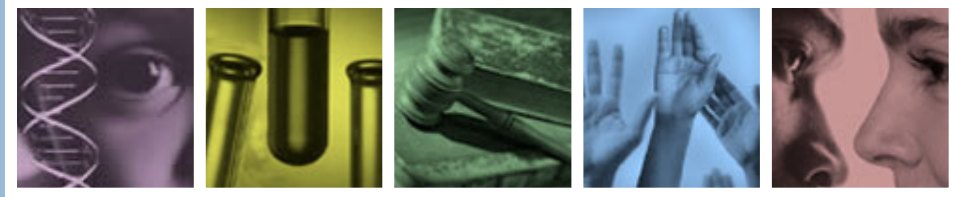
NOT whether technology is good/bad, allowed/banned, moral/immoral but rather Qs about risk/benefits and priorities.

- What is our approach to new biotechnologies: outright enthusiasm or “cautious optimism” or precautionary principle?
- What is the balance to strive for between social justice and personal liberties (individual choices)?
- What is the role for government in regulation/resource prioritization/safety? Or do we leave it to market allocation?

Cloning



Embryonic Stem Cells



Stem Cells



- Adult stem cell therapies – **GOOD!**
- Embryonic stem cell therapies w/ leftover IVF embryos – **GOOD!**
- Somatic cell nuclear transfer – **CAUTION!**
 - Cloning technology -- research cloning
 - # of fresh women's eggs
 - Expensive and individualized therapies

Eggs for research



Which comes first – the egg or the cure?

It could happen to you or your loved one:

- Diabetes
- Heart Disease
- Spinal cord injuries
- Parkinson's disease
- Blindness
- Strokes, AIDS, MS, cancer, among others

Thousands of Americans die everyday
from diseases that could potentially be
treated - or even cured - using stem cells

Women 21-35 years old needed
to donate eggs for stem cell
research project.

*(All procedures will be carried out at an accredited clinic by certified
medical professionals. Travel, hotel and other expenses covered)*

LET YOUR EGGS BE PART OF THE CURE!

Please donate your eggs. Call 202-315-3736

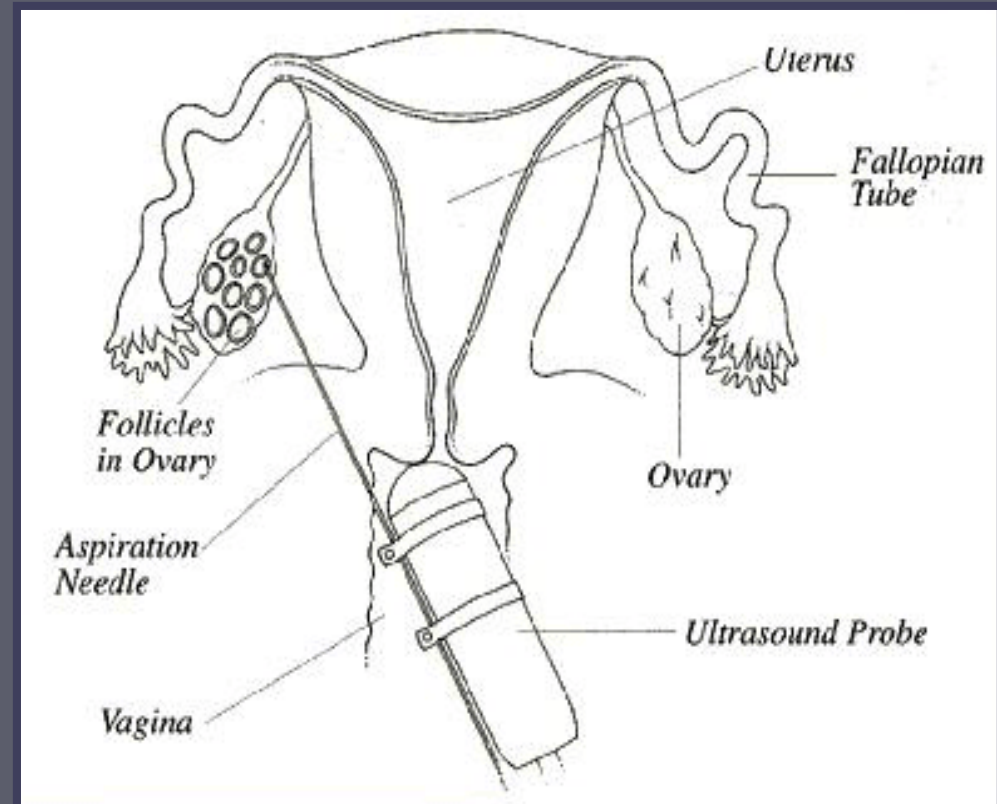
Current state of technology:

- Large number of eggs will be needed
- South Korea research scandal
 - Hwang said used 427 eggs; actually used 2,230
 - Involved ethical breaches
- CA SB 1260 – basic safeguards for women's health -- informed consent, women as research subjects

Egg extraction



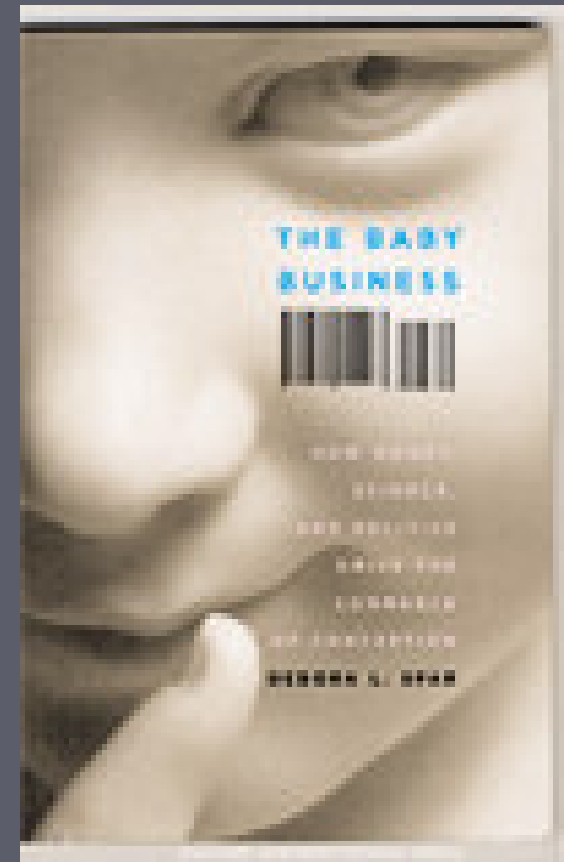
- Hormones used to “shut down” and “hyperstimulate” women’s ovaries to produce multiple eggs
- Some adverse health reactions
- No data on long-term health risks to women



Assisted Reproductive Technologies



- Benefits -- expands family formation options for many
- Concerns
 - Accessibility & equity (basic health care)
 - Unregulated in terms of health & safety – lack of data and oversight
 - Reproductive tourism & international markets – renting 3rd World wombs
 - Geneticizes family formation and ties



Recruiting egg “donors” for IVF



“EGG DONOR NEEDED: Professional warm couple looking for that special lady to help them create their family. Caucasian/Spanish background. Applicants must be in good health and top genetic makeup. Intelligent (SAT 1200+), dynamic, friendly, physically fit and physically attractive.”

UCLA campus newspaper

Help
infertile
couples
experience
the joys of
parenthood
and earn up
to \$50,000


**BECOME
AN EGG
DONOR**

We need healthy women
up to age 32.
**Compensation begins
at \$5,000!**

For more information,
please contact Liz at
(703) 698-3909 or via email
at eggdonor@givf.com.

To apply online, visit
www.gametedonors.com.

Confidentiality assured


GENETICS & IVF
Institute

Washington Express

Demand for Women's Eggs



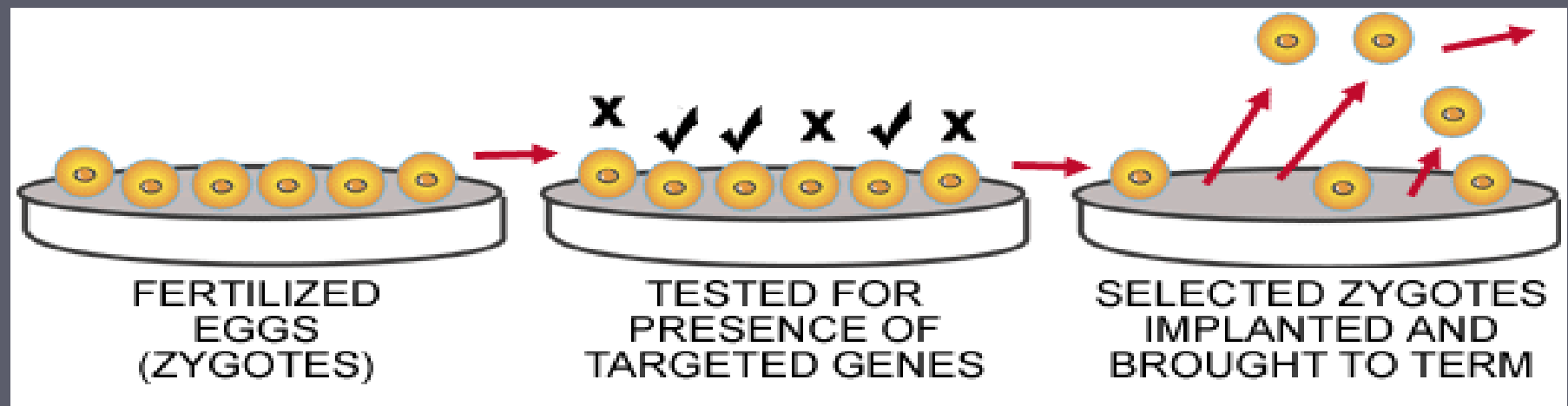
- **Eggs for fertility**
 - Recruitment in college newspapers; target young women
 - \$5,000-7,000/cycle; up to \$100,000 for “ivy-league” eggs
 - Reproductive tourism and international markets
- **Eggs for research (SCNT)**
 - 2,230 eggs for failed research in S. Korea
 - Eggs as the raw materials of research
 - No data on long-term health impacts (risk/benefit)
 - Compensation?

Pre-pregnancy selection technologies



Pre-implantation genetic diagnosis (PGD)

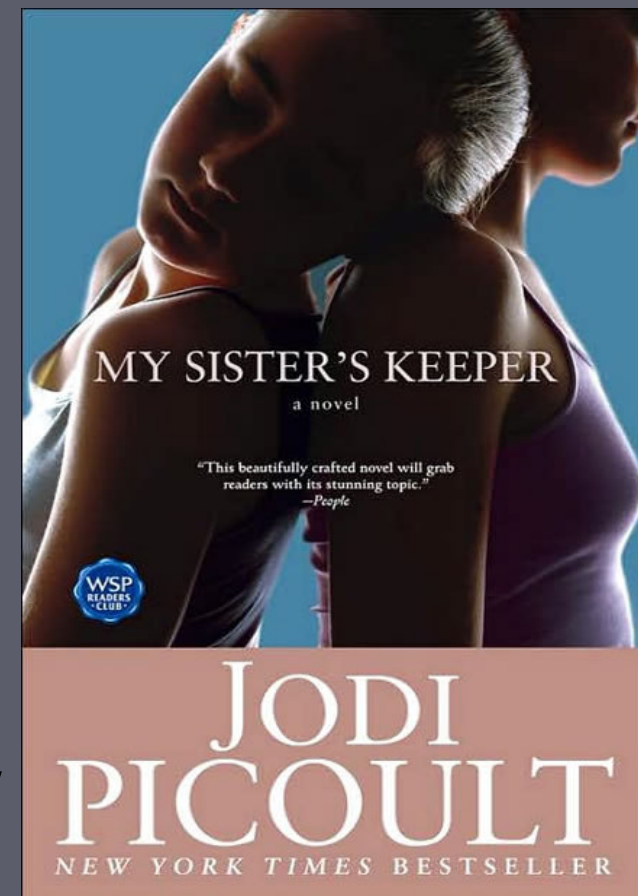
- In-vitro egg fertilization
- At day 3 (8 cells) a cell is extracted for testing
- Only selected (desired) embryos implanted



Pre-implantation genetic diagnosis (PGD)



- Developed for genetic “disability” de-selection
- More recently –
 - Sex selection
 - Late (adult) on-set diseases –
 - Alzheimer, diabetes
 - Tissue match for existing child needing transplant
- Normalizes genetic selection and desirability - “family eugenics”
- Reinforces medical model of disability



Pre-pregnancy selection technologies



- MicroSort® -- sorts sperm cells carrying Y-chromosome (male) from X-chromosome (female)
- Ads in *NY Times* and in-flight magazines
- Coming from India & China to unregulated U.S.

The MicroSort® Gender-Selection Program at GIVF

Do You Want To Choose the Gender Of Your Next Baby?



If you want to choose — or need to choose — whether your next baby is a girl or a boy, you may qualify for the MicroSort® gender selection procedure at the Genetics & IVF Institute (GIVF).

Prospective parents come from all over the world to GIVF in suburban Washington, DC. They choose this exclusive *scientifically-based* sperm sorting gender selection procedure, currently in an FDA clinical trial, for several important reasons:

- For prevention of genetic diseases
- For family balancing
- Results so far show 90% success rate for achieving girls and 75% for boys.
- FREE MicroSort for qualifying patients who use Donor Egg or Preimplantation Genetic Diagnosis at GIVF.
- For sensitive, personal attention from a caring staff of professionals, dedicated to the success of your family.

Couples also choose the Genetics & IVF Institute because we are the world's largest integrated provider of infertility and genetic services. Our expertise in the diagnosis and treatment of complex genetic and reproductive disorders is second to none.

To learn more about the Genetics & IVF Institute, and how the MicroSort® technology may help you select the gender of your next child — please visit us at:

www.givf.com

or call us at

1-800-277-6607

Now available in New York and other metropolitan areas through collaborating physicians. Call for details.

Caution: This procedure uses an investigational device limited by federal law to investigational use.

GENETICS & IVF INSTITUTE



Gender Monitor



- At 5 weeks test the mother's DNA to determine sex of fetus
- Results via internet
- “For the woman who can't wait to open her Christmas gifts” and “Family fun”



Technologies on the horizon



Non-inheritable genetic modification
changes genes in cells except sperm and egg cells
-- gene therapy, gene transfer, gene doping

Inheritable genetic modification
changes genes in sperm and egg cells, or early embryos --
designer baby technology, germline engineering

SCIENCE

Designer Babies

Scientists say that, with gene therapy, they may soon be able to cure a child's inherited disease before he is even born. But should they be allowed to create kids with made-to-order traits? BY SHARON BEGLEY

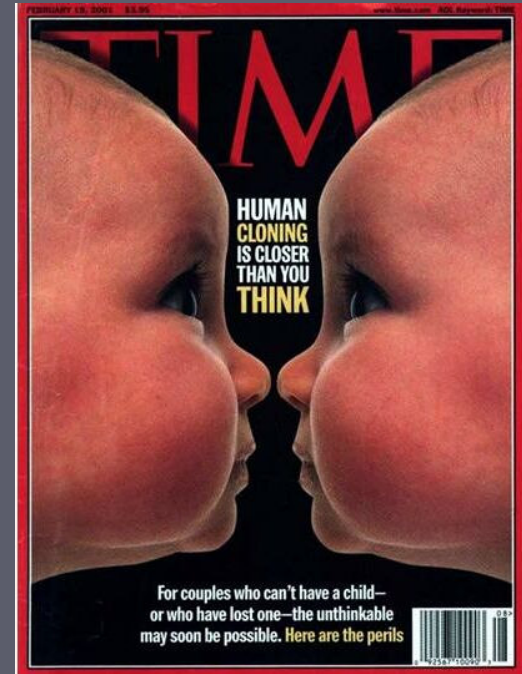
IT IS ONLY A MATTER OF TIME, ONE day—a day probably no more distant than the first wedding anniversary of a couple who are now teenage sweethearts—a man and a woman will walk into an in vitro fertilization clinic and make scientific history. Their problem won't be infertility, the reason couples now choose IVF. Rather, they will be desperate for a very special child, a child who will elude a family curse. To create their dream child, doctors will fertilize a few of the woman's eggs with her husband's sperm, as IVF clinics do today. But then they will inject an artificial human chromosome, carrying made-to-order genes like pearls on a string into the fertilized egg. One of the genes will carry instructions ordering cells to commit suicide (graphic). Then the doctors will place the embryo into the woman's uterus. If her baby is a boy, when he becomes an old man he, like his father and grandfather before him, will develop prostate cancer. But the cell-suicide gene will make his prostate cells self-destruct. The man, unlike his ancestors, will not die of the cancer. And since the gene that the doctors gave him copied itself into every cell of his body, including his sperm, his sons will beat prostate cancer, too.

Genetic engineers are preparing to cross what has long been an ethical Rubicon. Since 1990, gene therapy has meant slipping a healthy gene into the cells of one organ of a patient suffering from a genetic disease. Soon, it may mean something much more momentous: altering a fertilized egg so that genes in all of a person's cells, including eggs or sperm, also carry a gene that scientists, not parents, bequeathed them. When the pioneers of gene therapy first requested government approval for their experiments in 1987, they vowed they would never alter patients' eggs or sperm. That was then. This is now. One of those pioneers, Dr. W. French Anderson of the University of Southern California, recently put the National Institutes of Health on notice. Within two or three years, he said, he would ask approval to use gene therapy on a fetus that has been diagnosed with a deadly inherited disease. The therapy would cure the fetus before it is born. But the introduced genes, though targeted at only blood or immune-system cells, might inadvertently slip into the child's egg (or sperm) cells, too. If that happens, the genetic change would affect that child's children unto the nth generation. "Life would enter a new phase," says biophysicist Gregory Stock of UCLA, "one in which we seize control of our own evolution."

Judging by the 70 pages of public comments NIH has received since Anderson submitted his proposal in September, the overwhelming majority of scientists and ethicists weighing in oppose gene therapy that changes the "germline" (eggs and sperm). But the opposition could be a

What, me worry? DNA tricks may ease ethical concerns about 'playing God'

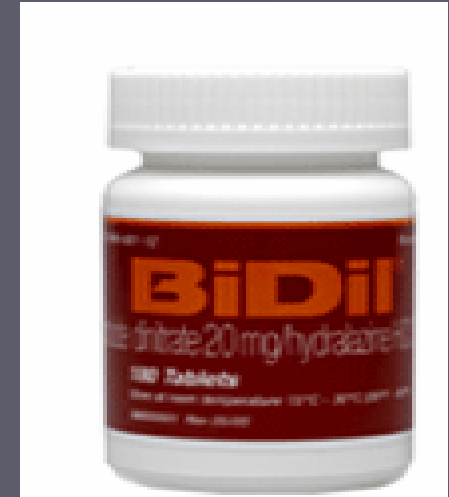
Cloning



Geneticization of race & health



- First race-based medicine
-- BiDil for African American heart disease
- Geneticization of health disparities and race



Re-biologicalization



- Geneticization of family ties
- Geneticization of health disparities
- Geneticization/technological fixes for social/environmental problems
- Increasing use of genetics to explain/justify differences:
 - Intelligence
 - Sexuality
 - Race

Social Justice & Progressive Concerns



- Reproductive health, rights and justice of women
- Health equity, access and priorities – “designer medicine” v. universal health care for all
- Geneticization of race and difference
- Reproductive tourism and markets -- international
- Lack of oversight, regulation and civil society debate
- Potential technological, market-based eugenics – breeding better people – “perfect” babies or “designer babies”

Women



- Pressures for “perfect” babies or specific types of babies
- Increasing demand for women’s eggs and reproductive materials -- health & safety risks, economic pressures
- Increased medicalization -- less control of one’s reproductive decisions & experiences
- Who is “choosing” in the marketplace and at what cost to women and society?

Opportunities



- Pro-active agenda setting
- Work cross-movements: women, people of color, LGBTQ, disability, health
- Ensure that basic social justice/progressive values at the core of this agenda -- equity, health & safety, inclusion, democracy, human rights
- Prevent potential eugenic outcomes

Biopolitics



- What is our approach to new biotechnologies: outright enthusiasm or “cautious optimism” or precautionary principle?
- What is the balance to strive for between social justice and personal liberties (individual choices)?
- What is the role for government in regulation/resource prioritization/safety? Or do we leave it to market allocation?

**How and when do we answer these questions?
Informed by what values?**