

Reproductive & Genetic Technologies

Causes in Common National Coalition Meeting

Panel on Assisted Reproductive and Genetic Technologies

May 30, 2007

Chicago, IL



Sujatha Jesudason

Center for Genetics and Society

Technologies and practices



- Selection technologies
 - Sex selection
 - Genetic testing and screening (PGD)
- Reproductive (Human) Cloning
- Embryonic Stem cells & research cloning
 - Women's eggs & embryos as commodities
- Inheritable genetic “enhancement” (designer babies)
- Geneticization of Race and health disparities
 - Race-based medicine: e.g., BiDiI

Sex selection



- MicroSort® -- sorts sperm cells carrying Y-chromosome (male) from X-chromosome (female)
- Costs about \$3,200 per try (most need 3 tries)
- 419 Microsort babies born
- Ads in *NY Times* and in-flight magazines

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



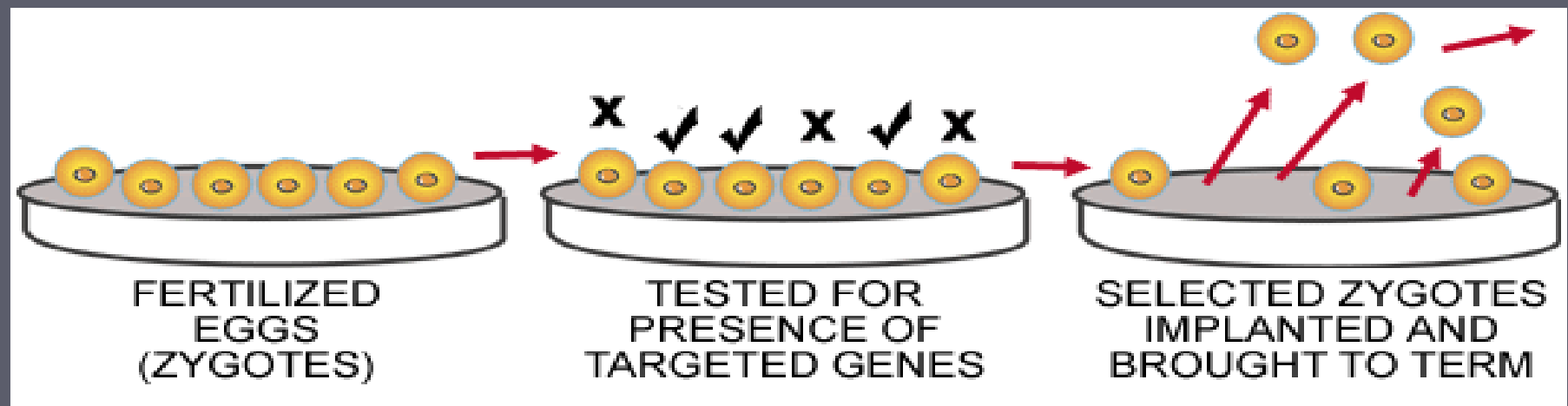
- At 5 weeks test the mother's DNA to determine the sex of baby
- Cost -- \$25 for kit & \$250-350 for DNA test
- Results via internet
- 2005



Pre-implantation genetic diagnosis (PGD)



- Using in-vitro fertilization, eggs are fertilized
- At day 3 (8 cells) a cell is extracted for testing
- Only selected embryos implanted
- No genes or embryos are modified



PGD



- Developed in the 1990s -- used to select for genetic conditions
- More recently –
 - Sex selection
 - Late (adult) on-set diseases – Alzheimer
 - Tissue match for existing child needing transplant
 - Likelihood of deafness in future generations
- Banned in a number of countries; unrestricted in the U.S.

Technologies on the Horizon



Research cloning

- Requires fresh eggs from women

Reproductive human cloning

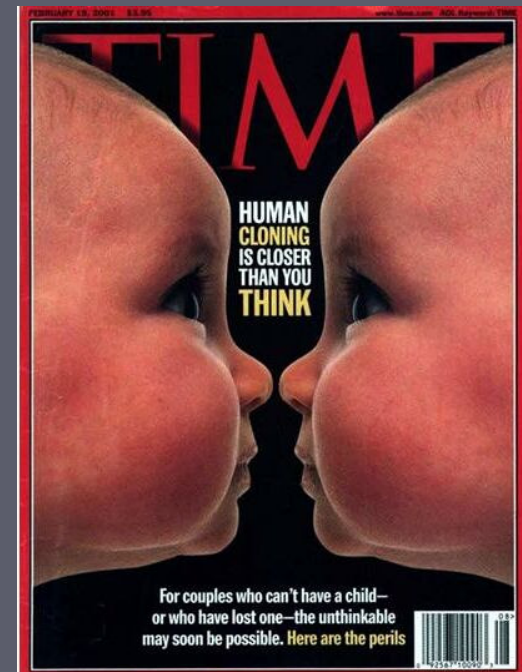
Non-inheritable genetic modification

- Changes genes in cells except sperm and egg cells

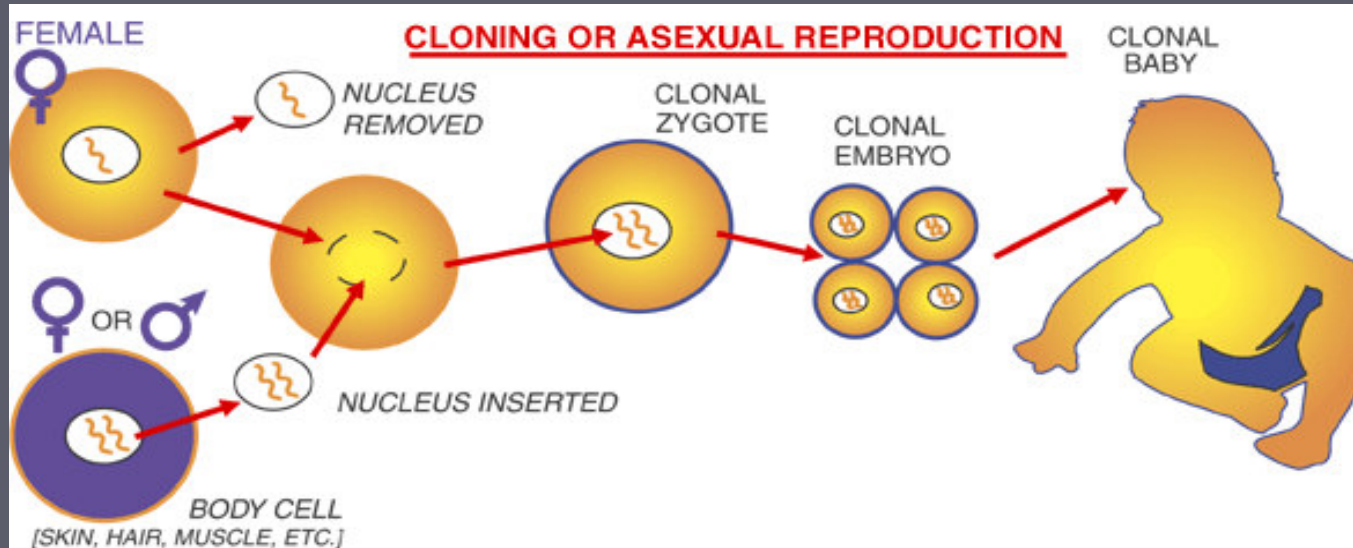
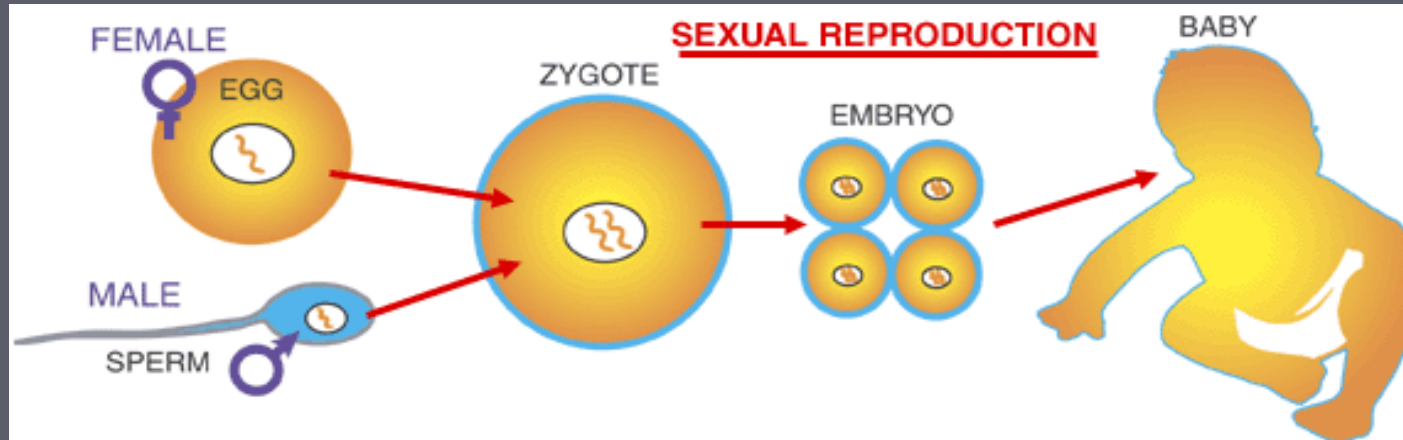
Inheritable genetic modification (IGM)

- Changes genes in sperm and egg cells, or early embryos

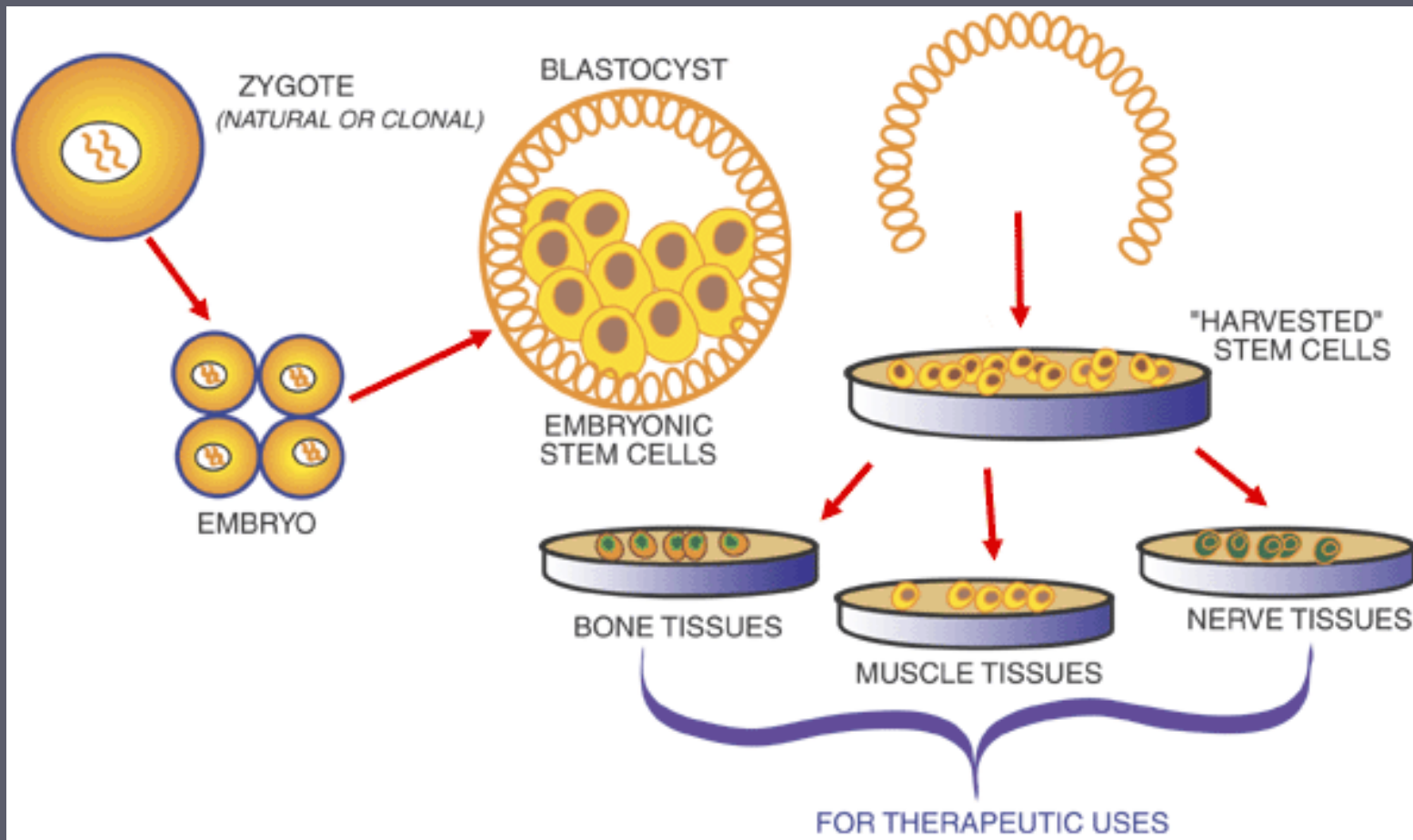
Cloning



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
 - # of women's eggs
 - Health equity

Current concerns about Stem Cell Research



1. Health care equity & priorities

2. Minimal oversight –

- Women's eggs
- Cloning technology

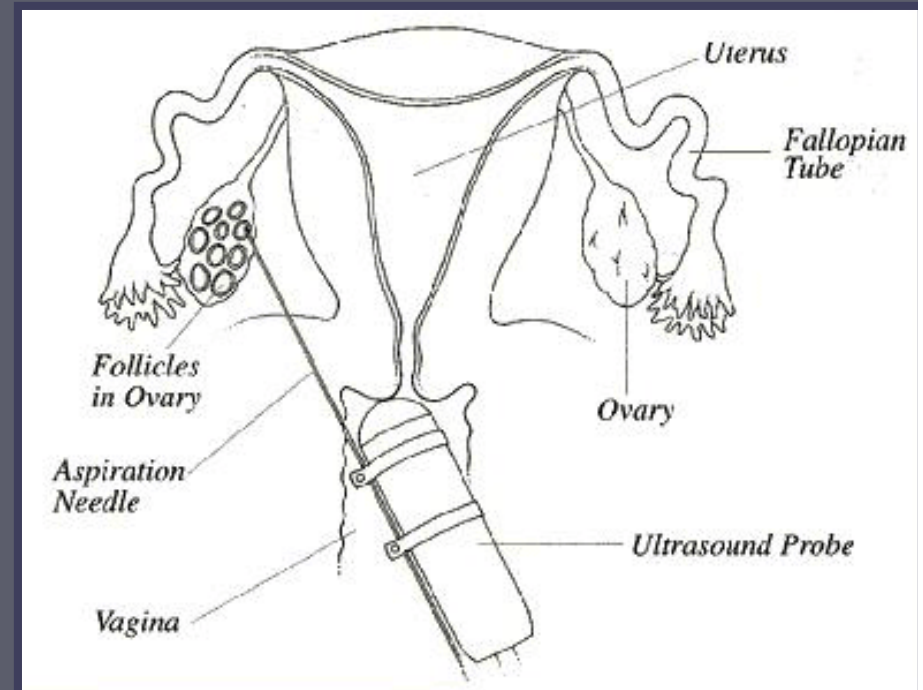


3. Abortion politics polarization –
unquestioning support on the left

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



Demand for Women's Eggs



- Eggs for fertility
 - “Donor” eggs, heavy recruitment in college newspapers
 - Usually \$5-7,000/cycle; up to \$100,000 for “ivy-league” eggs
 - Concerns about the markets for young women’s reproductive tissue
- Eggs for research (SCNT)
 - To date: 200-1600 eggs for failed research in Korea
 - Concerns about women’s reproductive tissue as the raw materials of research

Eggs for Fertility & Research



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**



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 expense covered)*

LET YOUR EGGS BE PART OF THE CURE!
Please donate your eggs. Call 202-315-3736

Two kinds of human genetic modification



1. Non-inheritable genetic modification changes genes in cells except sperm and egg cells -- Also called *gene therapy, gene transfer, genetic engineering, gene doping*
2. Inheritable genetic modification changes genes in sperm and egg cells, or early embryos -- Also called *designer baby technology, germline engineering*

Genetic Enhancement



THE FUTURE OF MEDICINE

Parents can now pick a kid's sex and screen for genetic illness. Will they someday select for brains and beauty too?

Designer Babies

By MICHAEL D. LEMMONICK

UNTIL JUST A FEW YEARS AGO, MAKING A BABY BOY OR A BABY GIRL WAS PRITTY MUCH A HIT-OR-MISS affair. Not anymore. Parents who have access to the latest genetic testing techniques can now predetermine their baby's sex with great accuracy—as Monique and Scott Collins learned to their delight two years ago, when their long-wished-for daughter Jessica was born after genetic prescreening at a fertility clinic in Fairfax, Va.

And baby Jessica is just the beginning. Within a decade or two, it may be possible to screen kids almost before conception for an enormous range of attributes, such as how tall they're likely to be, what body type they will have, their hair and eye color, what sorts of illnesses they will be naturally resistant to, and even, conceivably, their IQ and personality type.

In fact, if gene therapy lives up to its promise, parents may someday be able to go beyond wending out undesirable traits and start actually inserting the genes they want—perhaps even genes that have been crafted in a lab. Before the new millennium is many years old, parents may be going to fertility clinics and picking from a list of options the way one browses under air conditioning and chrome-alloy wheels. "It's the ultimate shopping experience: designing your baby," says biotechnology critic Jeremy Baillet-Latour, who is appalled by the prospect. "It's a society used to cosmetic surgery and psychopharmacology; this is not a big step."

The prospect of designer babies, like many of the ethical conundrums posed by the genetic revolution, is confounding the world as rapidly that doctors, ethicists, religious leaders and politicians are just starting to grapple with the implications—and trying to decide how they best avoid it all.

They still have a bit of time. Aside from gender, the only traits that can now be identified at the earliest stages of development are about a dozen of the most serious genetic diseases. Gene therapy in embryos is at least a few years away. And the genes or combinations of genes responsible for most of our physical and mental attributes have not even been identified yet, making the idea of engineering genes in or out of a fetus. Besides, say clinicians, even if the techniques for making designer babies are perfected within the next decade, they should be applied in the service of disease prevention, not improving on nature.

But what doctors intend is not necessarily what's going to happen. Indeed, the technology that permitted the Collins family to pick the sex of their child was first used to select for health, not gender per se. Adapting a technique used in livestock, researchers at the Genetics & IVF Institute in Fairfax took advantage of a simple rule of biology: girls have two X chromosomes, while boys have one X and one Y. The mother has only Xs to offer, so the balance of genes lies with the father—specifically with his sperm, which brings either an X or a Y to the fertilization party.

As it happens, Y chromosomes have slightly less than two Xs. So by ablating the sperm's sex with a synthetic, light-sensitive dye, the Virginia scientists were able to sort sperm by gender—with a high rate of success—before using them in artificial transmission. The first couple to use the technique was looking to escape a deadly disease known as X-linked hydrocephalus, or water on the brain, which almost always affects boys.

But while the technique is ideal for wending out this and other X-linked disorders, including hemophilia, Duchenne muscular dystrophy and Fragile X syndrome, most patients treated at Genetics & IVF want to pass out their families—a life-style rather than a medical decision. The Fairfax clinic has been willing to help, but such a trend doesn't sit well with some other practitioners. "Our view at the moment," says Dr. Zev Rosenwaks, director of the Center for Reproductive Medicine and Infertility at Cornell Medical Center in New York City, "is that these techniques should be used for medical indications, not family balancing."

But now that parents know that the technology is available, and that at least some clinics will let them choose a child's gender for nonmedical reasons, it may be too late to go back. In a relatively short time, suggests Princeton University biologist Leo Silver, whose book *Remaking Eden* addresses precisely these sorts of issues, sex selection may cease to be much of an issue. His model is in vitro fertilization, the technique used to make "test-tube" babies. "When the world first learned about in vitro decades ago," he says, "it was horrifying to most people, and most said that they

should be allowed to do it. But what doctors intended is not necessarily what's going to happen. Indeed, the technology that permitted the Collins family to pick the sex of their child was first used to select for health, not gender per se. Adapting a technique used in livestock, researchers at the Genetics & IVF Institute in Fairfax took advantage of a simple rule of biology: girls have two X chromosomes, while boys have one X and one Y. The mother has only Xs to offer, so the balance of genes lies with the father—specifically with his sperm, which brings either an X or a Y to the fertilization party.

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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 (emphyse). 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.

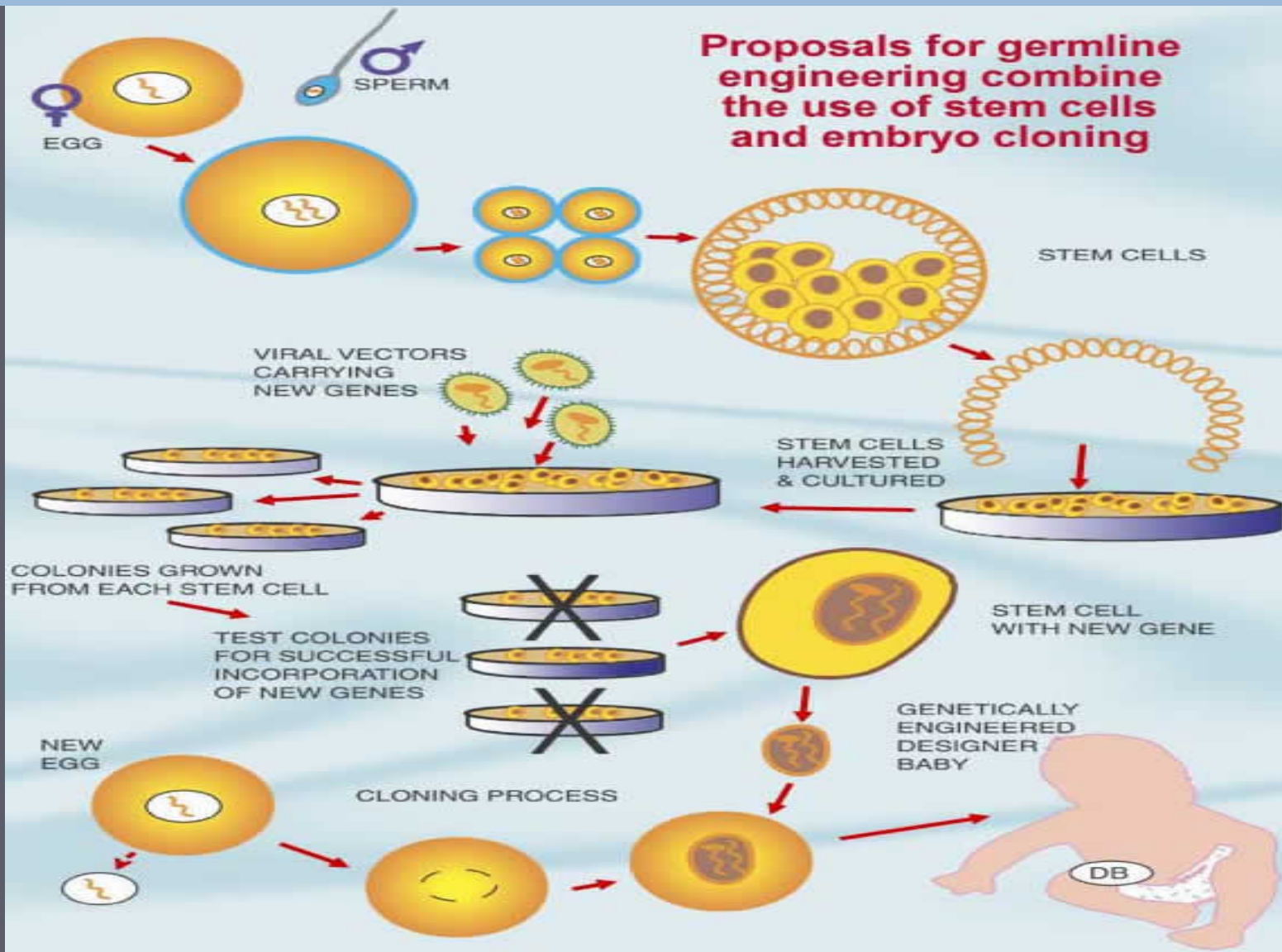
Genetic engineers are preparing to cross what has long been an ethical Rubicon. Since 1990, gene therapy has meant slipping a healthy gene into the cells of one organ of a patient suffering from a genetic disease. Soon, it may mean something much more momentous: altering a fertilized egg so that genes 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 into 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'



Inheritable genetic modification



Geneticization

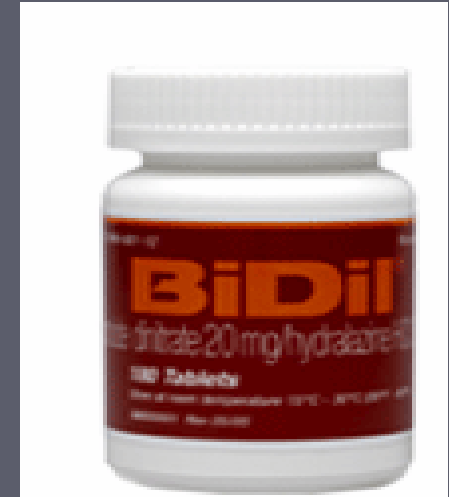


- Increased use of genetics to explain issues that have largely been understood as social, environmental, or influenced by other variables.
- Race
- Crime
- Sexuality
- Intelligence
- Mental Illness
- Alcoholism
- Shyness
- Obesity

Geneticization of race & health



- First race-based medicine
-- BiDil for African American heart disease
- Reducing racial health disparities to genetic differences – 99.9% of human DNA is alike



Race & genetics

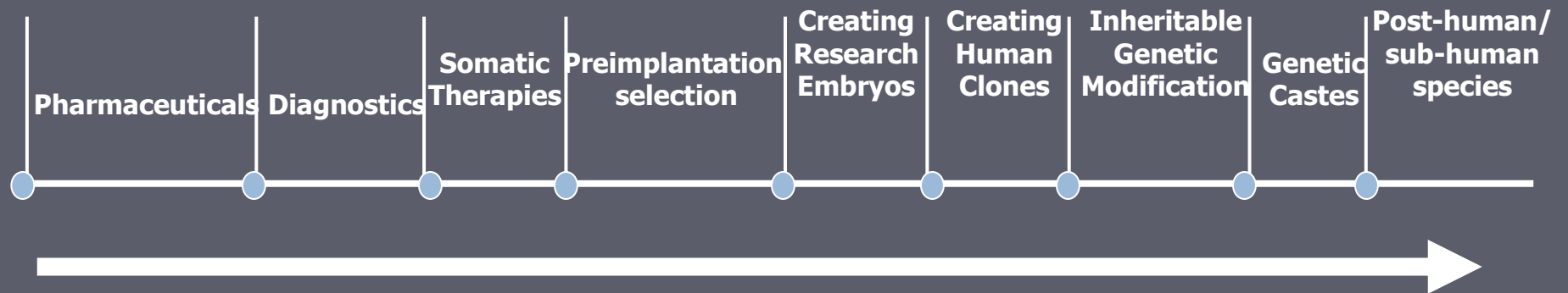


- Health & health disparities – genetics & environment
- DNA forensics, databases and dragnets
- Diversity in genetic research
- Genetics, race and marketing – DNA ancestry test, race-specific vitamins

Policy Question



Where do we draw the lines to ensure the benefits without the threats?



Concerns

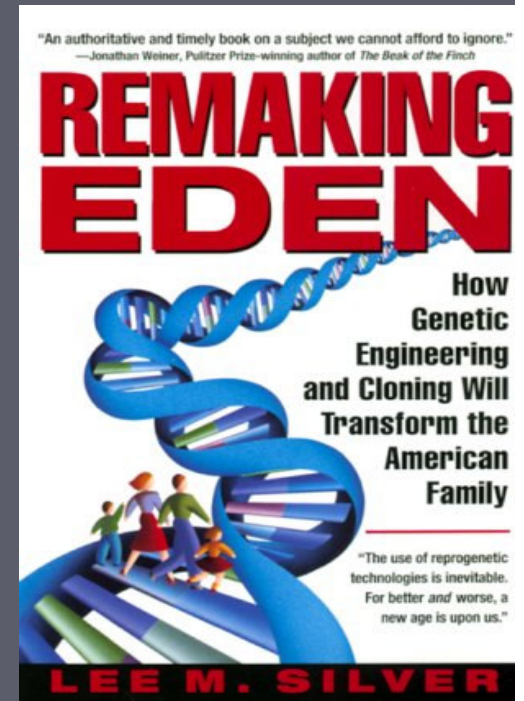


- Reproductive health, rights and justice
- Health equity and access – “designer medicine”
- Geneticization of race and difference
- Unethical medical experimentation
- **Consumer, market-based eugenics**

New Eugenecists



“...the economy, the media, the entertainment industry, and the knowledge industry [will be] controlled by members of the GenRich classNaturals [will] work as low-paid service providers or as laborers[Eventually] the GenRich class and the Natural class will become ...entirely separate species with no ability to cross-breed, and with as much romantic interest in each other as a current human would have for a chimpanzee.”



Concluding thought



“The final goal of reproductive engineering appears to be the manufacture of a human being to suit exact specifications of physical attributes, class, caste, colour and sex. Who will decide these specifications? We have already seen how sex-determination has resulted in the elimination of female fetuses. The powerless in any society will get more disempowered with the growth of such reproductive technologies.”

- *Saheli Women's Resource Centre, India 2001*