Engineering the Human Germline

An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children

Edited By Gregory Stock and John Campbell

New York Oxford Oxford University Press 2000

Sheldon Krimsky: "The Psychosocial Limits on Human Germline Modification"

Our thought exercise assumes that the health risks of human germline genetic alteration have been reduced to rates that fall below genetic abnormalities of natural reproduction. This means that the genetic modification of germ cells (GMGC), including deletion, addition, duplication, rearrangement, immobilization, or expression of gene sequences, coding or noncoding, would produce only the desired ("positive") outcome. Or, in the case that a genetic modification produces multiple genomic or phenotypic effects, it also assumes that those effects would not add any risks to the health and well-being of the individual (over his or her lifetime) beyond the background risks we attribute to natural conception. It shall also be assumed that any decision to undertake GMGC in procreation is strictly voluntary, has an economic cost, and has perceived benefits to the parents.

The most serious moral problem that I see in permitting the voluntary use of GMGC in human reproduction for any purpose whatsoever is that it will establish a role for genetic technology in raising aspirations of prospective parents for attaining a culturally defined but morally impoverished ideal of the genotype/phenotype of their progeny.

Among the most problematic cases are those involving the uses of GMGC for procreating children of a particular sex, body size, shape, or skin color. Offering people the opportunity to choose the phenotype of a child

will result in psychosocial pathologies, including deeper class and racial divisions within society.

The use of GMGC or other techniques to determine the sex of a child can, in a patriarchal society, lead to the superabundance of males with unanticipated consequences to traditional courtship patterns and gender equity. In many parts of the world where racial prejudice based on skin color is pervasive, some blacks may feel pressured to avail themselves of GMGC to insure light-skinned offspring. If this genetic modification were possible, it would reinforce social prejudices by connecting "medical procedures" with racist stereotypes that imply "whiter is better."

The same may be said of body types. Young adolescent girls, responding to media messages of "perfect body image," are prone to anorexia nervosa. Abnormal dieting and obsession with caloric intake are pervasive among normal preteens and adolescents. Women who recall their own pained adolescent years struggling with body image might be inclined, if offered, to choose a body type for their offspring that more closely resembles contemporary media images. While people may aspire to have children resembling our contemporary media "gods" and "goddesses," it would be a grave human error to use GMGC to narrow the genotype/ phenotype of the population. The public identification of genetics for this purpose reinforces the dangerous notion that there are universal standards of beauty and that science supports such standards. Even if there were but a few wealthy individuals who could afford to use such methods (assuming they were effective and safe), the symbolism that science has developed a reproductive technology that offers parents choices of body types for their offspring has profound psychosocial implications. And while cosmetic surgery responds to similar social cues and prejudices, it cannot affect the genotype and therefore will not narrow genetic diversity and serve a eugenics purpose. The psychosocial arguments against modifying germ cells for "enhancement" apply whether or not the alterations are transmitted to future generations. The availability of eugenic techniques in reproduction to a minority of affluent people will support the "geneticization" of a society, enabling an aristocracy with so-called proper genes to use it to their class advantage.

What about the selective use of GMGC for deleting or repairing lifedepriving genetic defects? Can we establish a reasonable and sustainable moral boundary that prohibits modifying clinically normal germ cells yet accepts the repair of abnormal ones? Theoretically, we might be able to justify a boundary that permits the use of GMGC in conjunction with in vitro fertilization exclusively for extreme genomic abnormalities. Realistically, our decentralized institutions providing reproductive services, including infertility clinics, sperm banks, and prenatal care, would make it virtually

impossible to maintain a boundary between the use of GMGC for lifethreatening genetic diseases, "enhancements," and the vast grey area in the middle. Just as surgeons have great latitude in the use of cosmetic surgery, and physicians can prescribe drugs for uses other than those approved in drug trials, if GMGC were approved for some uses of human reproduction, there would be no centralized system of control to prevent slippage.

Assume a best-case scenario: two heterozygotes, carrying single copies of a gene that is life-threatening for homozygotes, who do not wish to pass the gene to their offspring, seek relief through GMGC. We must ask if there are reasonable alternatives to germline modification, such as egg selection or sperm donation. If germline modification is the procedure of last resort for producing a healthy offspring, then we must balance the interests of parents with the broader social concerns that this first step will be the starting point for less agreeable (more morally ambiguous) forms of germline changes. With no assurance that our institutions and laws can prevent slippage in applying GMGC, any decision should weigh heavily on the side of "no first use." An international convention on proscribing the use of GMGC can set the framework for civil laws against eugenics on the part of signatory nations.

If you could do so safely, would you use an artificial chromosome to extend the lifespan of your child?

If I am given a hypothetical choice that allows me to endow my offspring with excellent health and longevity without compromising the child's personhood in any way, which does not compromise the health of my wife, which does not have any adverse implications on race, class, gender oppression, which is universally available, and for which there are no trade: offs (the procedure is just an add on), I would accept it. Of course, in vitro fertilization implies extracting eggs from a woman, which can have adverse effects. Perhaps we can add the proviso that the method adds no risk to the egg donor. I would do lots of things I don't ordinarily do (such as pray or live on a macrobiotic diet) if I had certainty it would create a better world or healthier children. Of course, I have to assume that if this were such a perfect and cost-free method to insure the health and longevity of my progeny, one that is universally available, many others would avail themselves of it and there would be no stigma associated with its use. It would be like a smallpox vaccination. Some people may be opposed on some principled grounds to vaccinations, but by and large having the availability to vaccinate against diseases has been a positive contribution to human civilization.

Perhaps some day there may be "genetic vaccinations" for men and women. The purpose of these "vaccinations" would be to repair mutations of germ cells in vivo before conception. If that ever were possible, it would make me rethink the "no germ line intervention" stand. Presumably, if the State were responsible for such "vaccinations," then a centralized guidance system could prevent its use for "enhancement" purposes that tend toward the medicalization of social or cultural ideals.