Quote to note

In the realm of bioethics, the evils we face are intertwined with the goods we so keenly seek. Distinguishing good and bad thus intermixed is often extremely difficult.

> —Leon R. Kass MD, PhD Chairman, The President's Council on Bioethics

Inside

Ask the ethicist Is this incest? By Arthur P. Wolf, PhD

The legal column

Behavioral genetics: Can we prevent crimes before they are committed? By Maxwell J. Mehlman, JD

Ethics and the humanities

The Diagnosis By Alan Lightman Review by James L. Bernat, MD **Dialogue** Why pharmacogenomics is good for ethics By Jeffrey Kahn, PhD, MPH **Natural law** By Peter J. Smith, MA, MD

The opinions expressed in the Medical Ethics Newsletter belong to the individual contributors and do not represent the institutional position of Lahey Clinic on any subject matters discussed.

Lahey

in collaboration with Dartmouth-Hitchcock Medical Center



Preimplantation genetic diagnosis: Beginning a long conversation

> By Thomas H. Murray, PhD President Erik Parens, PhD Associate for Philosophical Studies

Associate for Philosophical Studies The Hastings Center Garrison, New York

reimplantation genetic diagnosis (PGD) was first described in 1989 as a means to help couples who carry disease-related mutations avoid creating babies with those diseases. The first step in performing PGD is to create embryos by in vitro fertilization. After two or three days, the embryos have cleaved into six to eight cells. One or two of those cells are removed and their DNA is amplified by the method known as polymerase chain reaction, or PCR. The DNA is then analyzed to ascertain which embryos carry, and which are free from, the diseaserelated mutations. Only those without the mutation are considered for implantation.1

This "embryo biopsy" has thus far appeared to be without short-term adverse physical effects — though, as an editorialist in *The Lancet* observed, "it is too early to exclude the possibility of later effects."² Cystic fibrosis, Tay-Sachs disease, sickle cell anemia, the thalassemias, phenylketonuria, spinal muscular atrophy and myotonic dystrophy are among the disorders that have been analyzed with PGD thus far.³

The answer to the first ethical question in PGD turns on what one thinks about the moral status of a human embryo. If you regard embryos as having the same moral status as all other persons, then no form of PGD will be ethically acceptable for the simple fact that it entails destroying embryos albeit embryos with mutations that cause severe, typically life-threatening, diseases. If instead you think that embryos, while they deserve respect, do not have identical moral status to, for example, children or adults, then the moral status of embryos will not be an insurmountable barrier to using PGD (or to using *in vitro* fertilization in general).

While the embryo's moral status may be the first ethical question, it is by no means the only one. People who do not object to *in vitro* fertilization may nonetheless have deep concerns about some possible uses of PGD. Although the line between acceptable and unacceptable purposes may never be bright or universally recognized, it is our responsibility, as citizens and as stewards of this technology, to try to articulate what divides ethically acceptable uses from those that are not.

Two kinds of reasons are usually offered to support the use of PGD to select against disease-related traits. The first kind has to do with avoiding the burdens associated with disease. That kind of reason can be expressed in terms of avoiding the harm to the person who would live with the trait, to the family of the person who would live with the trait, or to the society in which

Preimplantation (Continued from Page 1)

that person would live. That sort of reason will be well known to anyone familiar with the justification of prenatal genetic diagnosis and selective abortion,⁴ which brings us to the second reason offered in support of PGD: it circumvents the psychological anguish and physical danger that accompanies selective abortion.

When many people imagine the ethically acceptable use of PGD, they have in mind a loving and healthy couple who wants to avoid having a child with a lethal disease. Tay-Sachs is often the example of choice. But PGD, of course, can be used for other, morally more complex, purposes. Two recent cases begin to make some of that complexity vivid.

The first case involves researchers helping a couple to have a child who would not be affected by early-onset Alzheimer's disease. In fact, it was the genetic profile of the mother — not the embryo — that put this case on the front page of major US papers. The prospective mother, who used PGD to create a child when she was 30, lost her own father to early-onset Alzheimer's when he was 42. It is likely that this child produced by PGD will, when she is still young, watch her own mother sink into dementia and die.⁵

It would be a better world if no young child ever had to live through the death of a parent; but, unfortunately, many children do. In this particular, real case, the couple thought exhaustively about the ramifications of their actions. Their genetic counselor told a Time magazine reporter that this couple was "10 times more thoughtful about what they chose to do than other people who have children."6 Perhaps effective treatments will be found to keep dementia at bay; the child's father, presumably, is fully committed to loving and raising his daughter whatever happens to his wife. The child, in any event, will be spared the fate that struck down her ancestors.

Nonetheless, this case points to a larger question that we cannot continue to avoid. To what extent should medical professionals or the state become involved in attempting to protect the well-being of children produced by techniques like PGD? In this case, the parents were both thoughtful and loving. What if they hadn't been? Should professionals or the state have said no, as they do in adoption cases where the child's well-being is thought to be in jeopardy? On the one hand, we have reason to worry about professionals or the state becoming involved in such intimate and important decisions. On the other, leaving such decisions to the market alone has its own perils.

The second case involving PGD raises further questions, not only about the well-being of children, but about the nature of the society in which those children will grow up.

Molly Nash was born with Fanconi anemia, a serious and eventually lethal blood disorder. When Molly's parents decided to have a second child with the help of PGD, they wanted that child to be free of anemia. They also decided to select an embryo that would be HLA (human leukocyte antigen) compatible with Molly - and thus a suitable cord blood donor. At first blush this case might appear to violate Immanuel Kant's famous dictum that a person should never be treated solely as a means, but always also as an end in himself or herself.7 The "solely" is key here. All of the available evidence suggested that this child's parents - Adam is his name - would love and raise him with the same devotion they give Molly. So, yes, in one sense Adam is a means to help his sister Molly; but he is also valued and loved - as an end in himself.

Although Adam Nash's parents had solid ethical reasons to use PGD as they did, nonetheless the Nash case is the first widely published use of PGD to select embryos based on a trait that was not pertinent to the health of the child that embryo would become. The clinician-researchers not only selected against Fanconi anemia, they also selected for a particular HLA haplotype.8 That Adam had immune system markers similar to Molly was important for her health, but not to Adam's. It does not require Stephen King's baroque imagination to foresee a time when it will be possible to test for traits that have nothing to do with the health of either a tissue recipient or the person being created.

We must begin now to think about the prospect of using PGD to select for non-health-related traits, or, more colloquially, "enhancements." The relationship between genes and complex traits such as stature or intelligence is itself so complex that it may never be possible to predict precisely which set of genes will yield which traits. Nonetheless, given human nature, and the entrepreneurial spirit of some scientists and clinicians, we can soon expect to find professionals promoting PGD as a means to improve a couple's chances of having a child with some desired trait, as well as couples eager to purchase those services.

One of the most important questions we face is what, if anything, is ethically problematic about selecting for such non-health-related traits or "enhancements?" After all, as individuals and a society we invest huge amounts of social resources to improve or "enhance" our offspring.⁹ We believe that there are serious ethical concerns raised when PGD is used to attempt to genetically "enhance" children. We take each of these key concepts in turn.

The first concern regards using genetic means to try to enhance children. The worry here is that focusing on genetics would exacerbate a tendency in our culture to understand human beings in mechanistic terms. So even if we might welcome being treated "mechanistically" if our leg breaks or our heart stops, we might nonetheless want to resist vigorously the tendency to let the mechanistic understanding permeate all aspects of our lives.

The second concern regards using genetic technology to try to enhance children. If we assume for the moment that access to such enhancements will be unequal, perhaps left to the market, then we should worry about fairness: parents with access to resources could purchase the increased chances that their children will have traits that will enable them to be still stronger competitors for scarce resources, increasing further the gap between those who have much and those who have little.

If, instead, we assume equal access to "enhancements," we still will need to grapple with, among others, the problem of complicity with suspect norms.¹⁰ For example, would it be acceptable to offer parents the option to select for the embryo with the greatest chance of becoming tall? In a society that favors tall people, parents might view PGD as a way to give their children the advantages that go with being tall. Using PGD for that purpose means bowing to and thus becoming complicit with the unjust norm of heightism. Do we want to live in a society that would sooner change the bodies of individuals

Ask the ethicist: Is this incest?

uestion: Janet M. is a 42-yearold single mother with two sons who are 4 and 6 years old. Both boys were conceived using anonymous donor sperm from different donors.

A few months ago, Janet, a successful advertising executive, moved from Los Angeles to San Francisco to take a new and more exciting job and to be closer to her widowed father, a healthy 70year-old retired high school English teacher. Janet's father, who now lives with her, has been helpful in caring for her sons while she works full time.

Janet comes to a fertility clinic to try for a third child, again using donor sperm. After one *in vitro* fertilization (IVF) cycle using donor sperm, Janet learns that she has poor quality eggs. To become pregnant, she would need a donated egg. Because she badly wants a genetic connection to her child, she requests that her father be the sperm donor. She would use an anonymous egg donor. In this manner she would be able to maintain a genetic link through her father and still experience pregnancy. Her father has agreed to this arrangement.

This request generated alarming and uncomfortable feelings for the IVF staff. While this would not be genetic or carnal incest, they felt that in some manner they might be violating the incest taboo because Janet would be giving birth to her father's child.

Should the IVF staff honor Janet's request?

Response: Anthropologists are generally agreed that incest is sexual intercourse between individuals related in certain prohibited degrees of kinship. Some would add "and/or affinity," but the core of the matter is proscribed sexual relations between kin. Strictly speaking, a woman's having a donated ovum impregnated with her father's sperm is not incest because it does not involve sexual relations with her father. But why then, does anyone object to the procedure? Why do some people insist that it is like incest? Does their reaction indicate there is something about it that ought not to be allowed?

One possibility is that the consequences are similar to those produced by incest. Obviously, there is no reason to fear that the biological consequences will be similar, but what about the social consequences? Accepting Freud's view that "an incestuous love choice" is in fact the first and regular one.1 many anthropologists have argued that the incest taboo exists to protect society from the deleterious consequences of these choices. One argument is that in its absence, families would become isolated "self-perpetuating units, over-ridden by their fears, hatreds, and ignorances."2 Another is that if it were not for the taboo, sexual rivalry between parents and children and between siblings would "subvert the most fundamental bonds of kinship on which the further development of all social relations is based."3

For reasons I will note below, I do not accept these arguments. But even if they were valid, they do not account for the unease people feel about the proposed procedure. The woman's family would not be isolated or its functioning subverted by her bearing a child carrying her father's genes. There is no more reason to predict dire social consequences than dire biological consequences. Yet the question remains: Why does the proposal make people uneasy? Why does it elicit what amounts to moral disapproval?

I think the answer is to be found in the work of the Finnish sociologist and philosopher Edward Westermarck.4 Westermarck argued that the dangers of inbreeding have selected for something that causes us to develop an aversion to sexual relations with people by whom or with whom we are reared. In the normal course of affairs, the aversion is experienced as a comfortable indifference. It only manifests itself as an aversion when incestuous behavior forces us to entertain the possibility of sexual relations with a parent or sibling. This is painful and prompts us to condemn the cause of our pain. Thus, in Westermarck's view, the moral

disapproval at the core of the incest taboo is rooted in our reaction to what he characterized as "living closely together from childhood."⁵

For the greater part of the 20th century Westermarck's argument was condemned to oblivion by Freud's claim that psychoanalytic investigations show "beyond the possibility of doubt" that incest is our first choice. The evidence that finally turned the tide of anthropological opinion against Freud came from two natural experiments - one in Israel and the other in Taiwan. The evidence from Israel says that when children are reared together in communal nurseries and allowed to choose their own sexual partners they never choose a childhood associate.⁶ The evidence from Taiwan says that when children are reared together and forced to marry the result is abnormally low fertility and an abnormally high divorce rate.7

Thus, following Westermarck, I think the reason some people are reluctant to allow the proposed procedure is because it arouses their aversion to sexual relations with their relatives. The procedure does not involve the women's having sexual relations with her father, but it does involve allowing her father's sperm to pass through her body. It is not incest, but it brings to mind the possibility of incest. It arouses an image of sexual relations between father and daughter, and, for many people, this is enough to transform a comfortable indifference into a painful aversion.

Should the requested procedure be disallowed because it arouses an aversion that prompts disapproval? In my view, no, if the only persons affected are the medical personnel who perform the procedure. The woman's request is not frivolous. A wealth of evidence says that we are so constituted as to act to perpetuate our genes. The only reason I can see for refusing the request is the possibility that the child will suffer if it becomes known that he or she is the product of an incestuouslike procedure. The reaction to the request is sufficient reason to fear that the child may be stigmatized. My recom*The legal column: Behavioral genetics: Can we prevent crimes before they are committed?*

By Maxwell J. Mehlman, JD

Professor of Law and Bioethics Case Western Reserve University Cleveland, Obio

cientists have long sought to explain human behavior in terms of inherited factors. Traits ranging from homosexuality to perfect pitch have been attributed to genes. Particular interest has focused on traits that lead to antisocial behaviors, such as committing crimes. If criminal tendencies were due, at least in part, to a person's genetic endowment, then genetic testing might identify potential criminals before they caused trouble, treatments might be devised to correct the biochemical errors that were responsible, and, perhaps, germ line engineering could be employed to eliminate the offending genes from the gene pool.

The search for an inherited basis for criminal and other socially undesirable behavior has led from phrenology to reports in the mid-1960s that an unusually high percentage of males institutionalized with violent or criminal tendencies possessed an extra Y chromosome. Most of these claims have been discredited. Identifying genes associated with behavioral traits is difficult because the traits are likely to be caused by the interaction of multiple genes and between genes and the environment, and because the traits themselves are not well-defined and cannot be identified consistently by different observers.

But the search continues. "Mounting evidence from animal and human studies shows that genetics has a role in human behavior," writes Charles Mann.¹

One stimulus for the hunt is the criminal defense bar, which is interested in raising "genetic defenses" on behalf of its clients in order to have them found not guilty or to reduce their punishment. The first genetic defense was asserted in the early 1970s, based on the XYY chromosomal abnormality.² The courts so far have rejected the XYY defense, but have indicated their general willingness to accept genetic defenses if the genetic condition meets various standards, such as that it "interferes substantially with the defendant's cognitive capacity or with his ability to understand or appreciate the basic moral code of his society."³

Occasionally the defense works. In one bizarre decision, a woman who murdered her son and tried to kill her daughter was declared not guilty by reason of insanity when she began to experience symptoms of Huntington's disease, even though the symptoms did not manifest themselves until seven years after the crime.⁴ Unfortunately, this case illustrates one of the pitfalls in this area: Judges and jurors typically have a poor understanding of genetic science, and might be led to accept a weak defense.

Apart from being asserted as a defense to culpability, associations between genes and undesirable behavior could make it possible to take preventive measures. For example, criminals could be tested for the offending genes and offered treatment to reduce their antisocial tendencies. Convicted criminals might be eager to volunteer, especially if treatment led to a reduction in their sentence or to early parole. An analogy is the use of the synthetic hormone Depo-Provera in sex offenders. Four states, including California, have enacted laws authorizing the use of this form of "chemical castration" as a condition of parole.5

But if geneticists discovered genes that actually caused people to engage in antisocial behavior, particularly violent crimes or sexual crimes against children, lawmakers might go even further. They might screen the population to detect potential offenders and treat them long before they committed crimes. This even could be incorporated into newborn screening programs. Or, we might test the children of convicted criminals and treat those who tested positive. If this proved too expensive or administratively difficult, legislatures simply might order that individuals with these heritable

genes be prevented from having children in the first place.

Ironically, we have been down this road once before. We tend to think that we are in the midst of a revolution in human genetics that began with the discovery of the double-helix configuration of DNA in 1953, or perhaps with the advent of the Human Genome Project in 1991, but the real beginning of the genetic revolution was the eugenics movement of 1870 to 1950.

Modern geneticists are understandably reluctant to associate themselves with this earlier foray into genetics and social engineering. As Allen Buchanan and his colleagues wrote in their book From Chance to Choice: Genetics and Justice, "the history of eugenics is not a proud one. It is largely remembered for its shoddy science, the blatant race and class biases of many of its leading advocates, and its cruel program of segregation and, later, sterilization of hundreds of thousands of vulnerable people who were judged to have substandard genes. Even worse, eugenics, in the form of 'racial hygiene,' formed part of the core of Nazi doctrine."6

What many people don't realize, however, is that eugenics was not the brainchild of Hitler and his cronies. The idea originated in Victorian England. Interest quickly spread across the Atlantic, where the movement received substantial financial support from leading citizens, including the Harriman, Carnegie and Rockefeller families. Far from being the brainchild of the Nazis, Hitler's eugenics program, which included compulsory sterilization, was heavily influenced by the eugenics movement in the United States.

The zenith of the eugenics movement in the United States was the 1927 Supreme Court case of *Buck v. Bell*, in which the Court, with only one justice dissenting, upheld the constitutionality of a Virginia law authorizing the state to sterilize inmates at the State Colony for

Ethics and the humanities: The Diagnosis

By Alan Lightman Pantheon, 2000

iterary depictions of illness

have an illustrious heritage. Within the genre of novelists' descriptions of undiagnosed, fatal illness, Tolstoy's The Death of Ivan *Ilvitch* occupies the premier niche. Now, Alan Lightman, Professor of Humanities and lecturer in physics at MIT, and author of Einstein's Dreams, has added The Diagnosis. This short novel depicts the personal agony of experiencing an undiagnosed illness within a 21st century context of high technology medicine and against a backdrop of the oppressive time pressure, materialism, anomie, and inhumanity of contemporary American urban life.

Bill Chalmers is a 40-year-old junior executive in a nondescript Boston financial district business with a suburban wife and teenage son. During a typical morning subway commute, he suddenly loses his orientation and memory and begins the descent into illness and the dissolution of his previously ordered life. The police believe him to be psychotic and take him to Boston City Hospital, from which he escapes. After losing his identity and dignity, his life further unravels with the loss of his job, his sense of self worth, and his understanding of his place in the world.

Lightman's description of the time pressure of contemporary American urban professional life is anxiety provoking. Every task is timed and competitive. Those who are late become the losers. He punctuates each page by noting the time by the minute on clocks and watches. Wasted time is a source of frustration and disgust. Even exercise and relaxation must be timed. The reader becomes exhausted by the relentless march of seconds and minutes. Chalmers' futile rush to meet each accelerating deadline, and the continuous and unstoppable accumulation of e-mails, phone messages, memos, and in-box tasks. The time pressure portrayed in the first half of the book is reminiscent of the intense, unrelenting,

and ultimately fatiguing rhythmic force of Ravel's *Bolero*.

Lightman portrays an inhuman, aggressive, uncaring society of people competing for money, prestige and space, despite the meaninglessness of their work. Chalmers' company sells "efficiency management," and he describes his own role as "I process information." At best, his colleagues are

"...like Socrates, Chalmers is condemned to die from "neglect of the gods," in this case, the gods of technology, money and power."

indifferent to the needs of others; at worst, they are cruel and utterly lacking in warmth or caring. It is into this milieu that Chalmers seeks understanding and solace for his illness. Instead, those seeking his place in the hierarchy trample him. Eventually, he is fired for the most egregious failure possible: getting behind in his work. His illness is not a mitigating factor. Everyone in society is replaceable and those who fail to perform are expendable.

Chalmers responds with outbursts of anger directed against technology and the tragic futility of his wasted life. He sees the structure of society itself as a machine. In one remarkable chapter in which Chalmers and his wife are invited to a large party at the suburban mansion of Marbleworth — capitalist-extraordinaire and owner of his downtown office building — Chalmers envisions Marbleworth as "the super machine who controls all the other machines."

Review by James L. Bernat, MD

Professor of Medicine, Dartmouth Medical School Hanover, NH

Chalmers fantasizes about destroying technology and even killing Marbleworth, evoking the spirit of the Luddites during the Industrial Revolution.

Lightman's depiction of physicians and academic medical practice is unflattering. Chalmers' physician, Armand Petrov, is a Massachusetts General Hospital internist who loves to order tests but hesitates to reach a diagnosis. As Chalmers inexorably deteriorates from limb numbness to outright paralysis, Petrov responds "we are making progress." This cryptic remark indicates only that he is excluding individual diagnoses by sequential testing but has not reached a specific diagnosis. The counterpoint of Petrov's diagnostic languor and the intense time pressure of the business world seems strangely ironic. Chalmers' evaluation by a MGH neurologist is particularly unhelpful. Eventually, he is referred to a psychiatrist who cryptically diagnoses unresolved anger.

Lightman treats the reader to several parallel subplots, including the conflicted relationship between Chalmers and his son and the virtual affair between Chalmers' wife and her unmet e-mail "lover." In an interesting and ultimately meaningful series of installments. Lightman retells from Plato's *Phaedra* the ancient story of the final few days of Socrates. He details the fascinating relationship between Socrates and his principal prosecutor, Anytus. The reader sees that, like Socrates, Chalmers is condemned to die from "neglect of the gods," in this case, the gods of technology, money and power. By the end of the book, the two plots converge when Chalmers finally achieves the same degree of acceptance and equanimity toward his anticipated death from an undiagnosed illness as Socrates exhibited facing his own death from hemlock.

Dialogue: Why pharmacogenomics is good for ethics

P rofessor Greely does an admirable job of articulating the ethical issues raised by pharmacogenomics (*Medical Ethics Newsletter*, Winter 2002), and I agree with most of the points he makes. That being the case, I would like to use my commentary to elaborate on a few of the ethical issues he pointed out in relation to pharmacogenomics, and to point out at least one he did not.

It seems to me that one of the most important lessons we may learn from the introduction of pharmacogenomics is that in terms of ethical issues, not all genetic tests are created equal. Much of the analysis of the ethical, legal and social implications of genetics has focused on the misuse of the information created by genetic testing. These concerns tend to focus on the discriminatory use of such information in hiring, firing, insurance eligibility, coverage and rate setting, and in stigmatizing individuals. As Greely points out, however, it is not clear how and why pharmacogenomic information is any more sensitive than many other non-genetic medical tests.

For instance, it is clear how a genetic test result that predicts a genetic disease like Huntington's disease could create psychosocial harms to the individual if the information becomes known. But such effects are difficult to foresee in the case of pharmacogenomic tests. A test result that predicts greater effectiveness and fewer side effects if a patient takes one class of painkiller versus another carries no greater risk of psychosocial harm than many other diagnostic tests, such as a complete blood count.

The assessment that pharmacogenomic tests pose fewer ethical challenges owes to the fact that most tests will not carry harmful secondary information, and because pharmacogenomic testing will be not be used to identify those with "genetic disease" but instead to assess where patients fall in a range of drug sensitivity, metabolism and side effects. A workable parallel might be blood typing, which applies to everyone and is important for determining what type of blood should be used in transfusions — but carries little if any harmful information. This characterization will not be true for every pharmacogenomic test, but will likely apply to the majority. Special protections can and ought to be employed for tests that pose special psychosocial hazards.

Consider for instance the case of a diabetic patient who takes a pharmacogenomic test that shows that he or she is a non-responder to the currently available therapies. Knowing that there is no effective medical treatment for a chronic disease like diabetes may have serious social effects, such as increased insurance rates (or refusal), impacts on employability, and so on. For pharmacogenomic tests with such potential negative impacts, firewalls ought to be established to safeguard results from misuse. Efforts are under way to create such protections, not only to guard genetic information but in preparation for the medical information privacy requirements contained in the Health Insurance Portability and Accountability Act.

Cases such as the untreatable diabetic identify another important aspect of pharmacogenomics - what Greely and others have identified as "orphan genotypes" — those genetic subgroups that realize lower response or greater side effects to particular drugs or classes of drugs than others. What should we do to address the orphan genotype problem? On one hand, members of such groups are actually made no worse off by having a pharmacogenomic test to explain what they likely already know from experience: that they realize lower responses or greater side effects to the drugs at issue. But knowing how large or small the group that falls into the orphan genotype, and whether the genotype falls disproportionately on one or more groups, may make all the difference as to whether pharmaceutical companies find it worthwhile to pursue drug research and development to treat patients with that genotype. Ethnic minority groups are rightly concerned that pharmacogenomics may not only explain why some drugs work less well for them, but that it could be used to justify decisions not to make research and development investments in drugs for "economically undesirable" populations.

What will no doubt be true is that even if some genotypes have greater frequency among certain ethnic groups, they will not be confined exclusively to those groups. So viewing difference at the level of genotype rather than ethnic group will not only lead to greater equity, but it will also be more accurate. The goal of public policy, through orphan genotype programs that parallel the current orphan drug program or some other policy approach, ought to be to work to find pharmacogenomically effective drugs for both major and minor genotypes.

Pharmacogenomics may well be one of the first widespread applications of genetic testing. As pharmacogenomic technologies are developed, they may show that many of the ethical issues identified as applying to genetic testing are manageable, as well as how to manage them. Maybe most important of all, pharmacogenomics may offer information that will help overcome some of the longstanding groupings of patients by crude and often medically misleading labels like race and ethnicity. This is all good news for both pharmacogenomics and bioethics.

Jeffrey Kahn, PhD, MPH

Director, Center for Bioethics Professor of Medicine University of Minnesota, Minneapolis

Natural law

T he fundamental building blocks that Daniel Callahan uses to create his new model of medicine are drawn from the natural law tradition and are generally compatible with Catholic social tradition.¹

Natural law developed as a theory in Western thought before the Christian era. For example, themes that became its foundational principles can be seen emerging in the tragedy, *Antigone*, by Sophocles (497-406 BCE) with its conflict between obedience to the king and obligations to other commitments. Natural law has taken many forms over the 23 centuries of its development and has had a diverse multitude of proponents both religious and secular.

A basic distillation of the natural law philosophy suggests that one question is the basis of formulating all natural law arguments: What does it mean to be a person? In responding to this question, moral reason must respect and be guided not by principles, deliberation or cultural norms, but by certain human capabilities such as rationality and the capacity for free choices. We can discover within ourselves the basis for such rights as liberty, zones of privacy and personal autonomy. Natural law presupposes that moral questions can not only be answered, but that reasonable people, regardless of their culture, time period, or personal experiences, will be able to find consensus because the answers to moral questions will be rooted in our shared human nature and formulated in a continuing body of (usually unwritten) collective knowledge.2,3,4

An example of this influence can be found in Callahan's appeal to an understanding of the term "repugnance" regarding genetic developments and

Legal Column (Continued from Page 4) -

Epileptics and Feeble Minded. The opinion, written by Chief Justice Oliver Wendell Holmes Jr. for the majority, culminated in the now-infamous exhortation: "Three generations of imbeciles are enough." ⁷

Against this grim historical background, modern interest in behavioral genetics understandably has sparked controversy. In 1993, a psychologist named David Wasserman obtained a grant from the NIH to hold a conference on genetics and criminal behavior. The plan drew protests from individuals who claimed that it was a thinly-veiled effort to attribute innate criminal tendencies to certain racial groups, particularly, African-Americans. The NIH took the unprecedented step of withdrawing the grant at the last minute, causing the conference to be cancelled. This led to the belief in academic circles that behavioral genetics, at least the focus on the association between genes and crime, was taboo. But Wasserman revised his proposal, received a larger grant from the NIH, and finally held the conference in 1995. Since then, there has been a flurry of books and articles exploring the new field.

their applications (*Medical Ethics Newsletter*, Fall 2001). By appealing to a reasoned approach to an appropriate use of emotions as a guide to moral formulations, Callahan is echoing the arguments that are and were the bedrock foundations for those who created the systems of natural law ethics. He is recognizing that natural law is not a divisive or sectarian methodology, but rather is an appeal to common reason and experience.

One reading of this view is that natural law could be adopted as a common starting point (and not as "the final word") for discussions in medical ethics for the following reasons: it has a universal appeal; it can be clearly expressed in nonsectarian language; and it has a history and stability that helps to prevent the slide towards absolute relativism.

> **Peter J. Smith, MA, MD** Assistant Professor of Clinical Pediatrics, Section of General Pediatrics and MacLean Center for Clinical Medical Ethics The University of Chicago

The shadow cast by eugenics still lies over behavioral genetics. But the allure of crime prevention remains as well: identify persons with inherited antisocial disorders before they misbehave, and modify their behavior prophylatically. If continued genetic research makes this feasible, the question is whether behavioral modification can be conducted in a fashion that comports with the individual rights guaranteed under the Constitution, such as the right of equal protection of the laws and the rights to be free from unreasonable search and seizure and from cruel and unusual punishment.

¹ Mann CC. Behavioral genetics in transition. *Science* 1994;264:1686.

² *People v. Tanner*, 91 Cal. Rptr. 656 (Cal. Ct. App. 1970).

³ *People v. Yukl*, 372 N.Y.S.2d 313 (N.Y. Sup. Ct. 1975).

⁴ Associated Press. Disease cited in murder acquittal. *Cleveland Plain Dealer* 1994; Sept. 29:A6.

⁵ See Stadler A. Comment, California injects new life into an old idea: taking a shot at recidivism, chemical castration, and the constitution. *Emory Law J* 1997:46;1285.

⁶ Buchanan A, Brock DW, Daniels N, Wikler D. *From Chance to Choice: Genetics and Justice.* Cambridge: Cambridge University Press, 2000:27.

7 Buck v. Bell, 274 U.S. 200 (1927).

¹ Callahan D. *False Hopes*. New York: Simon & Schuster, 1998.

² Curran CE, McCormick RA. From Foreword to Readings in moral theology. In *Natural Law and Theology*. Paulist Press, 1991.

³ Pope SJ. Gill R (ed): *Natural law and Christian Ethics*. In The Cambridge companion to Christian ethics. Cambridge: Cambridge University Press, 2001:77.

⁴ D'Arcy E. Reich W (ed): *Natural law. In The Encyclopedia of Bioethics, Vol. III.* New York: Macmillan Publishing Company, 1987:1133.

Ask the Ethicist (Continued from Page 3)

mendation is to allow the procedure but warn the woman that she may cause her child harm if she reveals the source of the sperm.

Arthur P. Wolf, PhD

Professor of Anthropological Sciences Stanford University

utcome: The fertility clinic decided not to go through with the procedure because of the complex psychological relationship between Janet and her father. Janet decided not to pursue IVF with donated sperm from another source.

¹ Freud S. Riviere J (trans). *A General Introduction to Psychoanalysis*. New York: Pocket Books, 1920:221.

² Levi-Strauss C. The family. In Shapiro HL (ed): *Man, Culture, and Society.* New York: Oxford University Press, 1960:278.

³ Malinowski B. Culture. In *Encyclopedia of the Social Sciences*. New York: Macmillan, 1930, vol. 4:630.

⁴ For a detailed account see: Wolf AP. *Sexual Attraction and Childbood Association: A Chinese Brief for Edward Westermarck.* Stanford, CA: Stanford University Press, 1995.

⁵ Westermarck E. *The History of Human Marriage*. 5th ed., rev., 3 vols. New York: Allerton, 1922, vol. 2:192.

⁶ Shepher J. Mate selection among second generation kibbutz adolescents and adults: incest avoidance and negative imprinting. *Arch Sex Behav* 1971:1(4);293-307.

⁷ The most recent evidence is summarized and discussed in: Wolf AP, Durham W (eds): *Inbreeding, Incest and the Incest Taboo: The State of Knowledge at the Turn of the Century.* Stanford, CA: Stanford University Press, in press.

Preimplantation (Continued from Page 2)-

than change the unjust and unjustifiable attitudes that give rise to the desire to change those bodies?

The third concern regards what it will mean to use genetic technology to try to enhance children. Would using PGD for the sake of enhancement exacerbate the tendency of parents to have unrealistic expectations of their children? Note: there is nothing new about this tendency. The question is, will PGD exacerbate it, and if it did, what would that mean for the well-being of children — and for parents?

The questions raised by PGD do not have easy answers. If anything, their difficulty reflects their complexity and significance. We are at the beginning of what will be a very long, important and interesting conversation. \Box

¹ Elias S. Preimplantation genetic diagnosis by comparative genomic hybridization. *N Engl J Med* 2001;345:1569-71.

² [Editorial] Preimplantation donor selection. Lancet 2001;358:1195.

³ Elias S. Preimplantation genetic diagnosis by comparative genomic hybridization. *N Engl J Med* 2001;345:1569-71.

⁴ Parens E, Asch A (eds). *Prenatal Testing and Disability Rights*. Washington, DC: Georgetown University Press, 2000.

⁵ Towner D, Loewy, RS. Ethics of preimplantation diagnosis for a woman destined to develop early-onset Alzheimer's disease. *JAMA* 2002;287:1038-40.

⁶ Gibbs N. Dying to have a family. *Time* March 11, 2002:78.

7 Murray T. The Worth of a Child. Berkeley and Los Angeles: University of California Press, 1996.

⁸ Verlinsky Y, Rechitsky S, Verlinsky O, Masciangelo C, Lederer K, Kuliev A. Preimplantation diagnosis for Fanconi anemia combined with HLA matching. *JAMA* 2001;285:3130-3.

⁹ Buchanan A, Brock D, Daniels N, Wickler D. *From Chance to Choice: Genetics and Justice.* Cambridge: Cambridge University Press, 2000.

¹⁰ Little M. Cosmetic surgery, suspect norms, and the ethics of complicity. In Parens E (ed): *Enbancing Human Traits.* Washington, DC: Georgetown University Press, 1998.

Medical Ethics

The Lahey Clinic Medical Ethics Newsletter encourages reader participation. We welcome comments for our "Dialogue" column and invite submission of ethical dilemmas for "Ask the ethicist." Send correspondence and requests for complimentary subscriptions to David Steinberg, MD.

David Steinberg, MD, Editor Lahey Clinic Medical Center 41 Mall Road, Burlington, MA 01805 david.steinberg@lahey.org

James L. Bernat, MD, Assoc. Editor Dartmouth-Hitchcock Medical Center One Medical Center Drive Lebanon, NH 03756

Patricia Busacker	Editorial Board
Managing Editor	Diane M. Palac, MD
	Thomas J. Prendergast, MD
David M. Gould, Ese	q. Paul Reitemeier, PhD
Legal Editor	James A. Russell, DO
	Andrew G. Villanueva, MD

Gloria G. Barsamian, MA Circulation Manager

Generous funding for the Lahey Clinic Medical Ethics Newsletter is made in memory of Harold Karp, by the Karp Family Foundation. This publication is partially funded by the Robert E. Wise, MD Research and Education Institute.

The Lahey Clinic Medical Ethics Newsletter can be found on the Lahey Clinic Medical Ethics website at www.lahey.org/Ethics/

Lahey

Non-Profit Organization U.S. Postage PAID Boston, MA Permit No. 9



41 Mall Road Burlington, MA 01805