Medical Ethics

Spring 2001

Quote to note

"Are we going to allow the industrialisation of Life itself, redesigning the natural world for the sake of convenience and embarking on an Orwellian future? And, if we do, will there eventually be a price to pay?"

— Charles, Prince of Wales

Inside

Ask the ethicist
Family demand for futile treatment
By Lawrence J. Schneiderman, MD 3

The legal column
Informed consent for stem cell research using frozen embryos
By Dena S. Davis, JD, PhD 4

Ethics and the humanities
Wit
By Margaret Edson
Review by
Lois LaCivita Nixon, PhD, MPH 5

Dialogue
Implantable brain chips — will they change who we are?
By Daniel C. Dennett, PhD, Ellen M. McGee, PhD, and Gerald Q. Maguire, Jr., PhD 6

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 CLINIC
in collaboration with
Dartmouth-Hitchcock
Medical Center

Genetically modified organisms

By David Magnus, PhD
Professor, Center for Bioethics
University of Pennsylvania, Philadelphia

Debate among policy makers and experts about genetically modified organisms has tended to frame the issue in terms of risks and benefits; this circumscribes the role of values in the debate and transforms the issue into a largely scientific one that should be restricted to experts. Scientists tell us what the benefits and risks are and whether the new technology is worthwhile. Critics often respond by noting that values can play at least some role even within this framework. The questions of how much risk is too much, what sorts of benefits are worthwhile and to what extent are they valued, and, above all, how much uncertainty is acceptable, are all issues that allow values to be introduced. Even so, the role of values is fairly limited in this way of framing debates.

There is little doubt that the creation of genetically modified organisms can offer many advantages. Current genetically modified organisms have included crops that are largely of benefit to farmers and are not clearly of broad public value. That situation will soon change as future genetically modified organisms will include: foods that have far greater nutritional benefit, crops that can grow in regions with poor soil that currently cannot support subsistence agriculture, cattle whose milk offers pharmaceutical benefit, foods that are more desirable in terms of traits that the public wants (e.g., Brussels sprouts that taste like chocolate). The market forces that largely determine which of these products are developed are complicated. For example, the traits that may be needed to feed a starving world are different than the traits that farmers in the United States want, and both may differ from the characteristics that the paying public supports.

Most criticisms have focused on two issues. First, there is concern about food safety. What impact will genetically modified organisms have on the health of those who eat them? The new technology makes it possible to cross species barriers with impunity. Will a shellfish gene placed in a tomato cause allergic reactions? The recent scare over StarLink corn is instructive. "Bt corn," a common genetically modified organism, includes a gene from *Bacillus thuingienis*, which produces a pesticide that kills the European corn borer. One of the problems with Bt corn is that it is likely that insects will soon develop resistance. StarLink is a new variation of Bt that includes a protein, Cry9C, that does not break down as easily in the body. It may therefore postpone resistance. However, it also has some characteristics of food allergens.

The fact that it will remain in the body longer increases the risk of allergic reactions (though there are no verified cases). StarLink corn was approved for animal feed, but not for human consumption. It is difficult if not impossible to keep the food supply for animals and humans separate. The feed is often in the same silos and at least some of the corn from one field can send seed to another.

(Continued on Page 2)

Genetically Modified *(Continued from Page 1)*

The result has been the discovery of small amounts of StarLink corn throughout the food supply. In addition to allergic reactions, some critics worry that each new generation of pesticide producing genetically modified organisms could lead to a build-up of harmful poisons in the body that might, for example, cause mutations or cancer.

A second set of concerns focuses on the environmental impact. First, there are worries about gene flow — the movement of genes from one population to another. The same genes that may one day make it possible for plants to grow in poor, salty soil or in relatively arid regions could create an ecological nightmare if they should be introduced to other plants. This can happen through interbreeding between genetically modified plants and plants from different but closely related species (out-crossing). For example, genetically modified wheat could cross with native grasses in South America to alter the make-up of the ecosystem and potentially create "super-weeds." Even in the absence of gene flow, the genetically modified organisms themselves could become super-weeds as a result of the traits that make them better suited to new habitats.

Another environmental trade-off for technology that makes it possible to produce sustainable agriculture in regions where it cannot "naturally" flourish is a significant risk of loss of biodiversity (a desirable seed is likely to be planted over millions of acres leading to monoagriculture) and the unchecked spread of plants into unintended regions. In addition to these concerns over the ecosystem and the creation of super-weeds, there is a worry over the potential impact of some genetically modified organisms on non-target organisms. Cornell University researchers found that pollen from Bt corn could kill the larvae of monarch butterflies who ingested it. This raised the fear that these engineered crops could kill butterflies and other non-target organisms. The results of subsequent field research to determine whether Bt corn really represents such a threat outside of the laboratory have been mixed.

Similarly, creating genetically modified animals and fish could lead to problems. Genetically engineered salmon could lead to the widespread introduction of new genes into wild fish runs. If the genes spread sufficiently (the very large number of fish normally introduced to rivers from "fish farms" tend to swamp the relatively smaller number of "wild" fish), they could introduce new vulnerabilities to disease and create unanticipated problems. The problem of "killer bees" was a result of laboratory organisms that escaped into the wild. Genetically modified mice and other mammals could create pests that will be much more difficult to eliminate.

Genetically engineered microorganisms present even greater environmental and health concerns. It will soon be possible to engineer bacteria and viruses to produce deadly pathogens. This could well open a new era in biological weapons in addition to the environmental problems that could result from the release of organisms into the environment. It has been a number of years since the Supreme Court allowed the patenting of a genetically modified bacterium that could eat oil. The environmental assessment of the widespread introduction of engineered microorganisms has only barely begun to receive attention.[1]

There are inadequacies in the regulatory framework that exists for genetically modified organisms. The present system is quite complex — organisms that have been modified to give off a pesticide fall under the jurisdiction of the Environmental Protection Agency (EPA), while an organism produced to express a gene to provide a nutritional benefit falls under the Food and Drug Administration (FDA). There is a growing sense that the FDA, Department of Agriculture, and EPA are not sufficiently rigorous or consistent in how they regulate genetically modified organisms and that there should be a single set of standards that more closely resembles the way the FDA handles drug development. The single most important factor for the differences between European and American attitudes in this matter (there is much more widespread opposition in Europe) is the amount of confidence in the regulatory institutions that protect the food supply. After "mad cow disease," Europeans do not trust their governments to provide safe food. A similar loss in confidence among U.S. consumers could have a similar effect.

There is much that can be said about the arguments in favor and against each potential risk and benefit. However, this way of framing the issue is not the way people seem to think about genetically modified organisms (or biotechnology generally). There seems to be a moral and even religious aspect to this debate that may be more important than a simple risk and benefit analysis can capture. When a sheep named Dolly was cloned from an adult cell, the widespread hysteria over cloning had very little to do with any analysis of the risks and benefits of the technology. Rather, there was a clear sense of "moral repugnance" that was expressed in a variety of ways. Similarly there is evidence that the fundamental framing of the genetically modified organism issue is in similar terms (and in fact is a related response). The term "Frankenfoods" suggests the modern Promethean myth — human hubris in the pursuit of knowledge can lead to our own unwitting destruction. Talk of "playing God" permeates and underlies the genetically modified organism debate just as it does the cloning controversy.[2] Indeed there is at least some empirical evidence to back up the claim that people are primarily motivated by moral concerns when they oppose genetically modified organisms Those who think in terms of risks and benefits tend to be at least cautious supporters of the technology.[3]

Leon Kass and others have argued that, in the context of cloning, we should give great weight to the moral repugnance of the public.[4] On this view, the visceral response is either significant for its own sake or, at a minimum, a way of capturing a whole set of objections that are difficult to articulate but clearly perceived. On the other hand, there are those who object to this type of concern as irrational. This type of visceral response tends to be ephemeral — as people become used to the technology, the concern dissipates. On this view, concern over "playing God" is nothing more than prejudice against the new and unfamiliar.[5]

(Continued on Page 8)

Ask the ethicist:

Family demand for futile treatment

Lawrence J. Schneiderman, MD
Professor, Department of Family and Preventive Medicine and the Department of Medicine

Question: JB, a 53-year-old man, had progressive liver failure associated with hepatitis C. During evaluation for a liver transplant, a biopsy disclosed liver cancer. Consequently, he was no longer considered a candidate. He developed pulmonary failure and renal failure and is now in the intensive care unit (ICU), comatose, ventilator dependent and requiring vasopressor medications to sustain his blood pressure. His physicians agreed that treatments aimed at life prolongation were futile and that comfort care should be the goal. However, members of his family repeatedly voiced their strong opposition to withdrawal of life-support. They also refused to agree to a Do Not Attempt Resuscitation order, insisting that cardio-pulmonary resuscitation be attempted if his heart stopped and dialysis be provided if necessary.

When the physicians suggested that the family might wish to obtain their own outside consultation or involve religious counseling, they refused. When asked what the patient himself would want, one son stated that JB had once demanded life-support for an infant who the doctors allegedly claimed was dying and the baby miraculously recovered. Therefore, he was sure his father would want aggressive measures in hope of a similar miracle. What would you do if you were the physician?

Response: The right of patients capable of decision-making (or, when appropriate, their authorized surrogates) to refuse unwanted treatment is now clearly established in ethics and the law. But what about the reciprocal situation? Do patients (or their surrogates) have a right to *demand* any treatment? Specifically, do they have the right to demand a treatment judged by physicians to be futile? What if the goal of the patient or family is a miracle, or life confined to the ICU, or even permanently unconscious life? Are there patient goals that do not comport with medical goals, hence should not be considered obligatory for the physician? Exploring these issues has forced us to revisit the doctor-patient relationship in a very fundamental way.[1]

First, we have to consider the problem of uncertainty in medicine. JB's loved ones hope for a miracle and the son claimed that JB was witness to one. "How can you be absolutely certain my father won't miraculously recover?" To this question, JB's physicians must admit they can never be absolutely certain. But based on empirical experience they have concluded that recovery from his present state is not a realistic possibility. Attempting aggressive life-prolonging treatments would so likely cause him harms, burdens and suffering that it would violate both the principles of non-maleficence (avoiding harm with no benefits) and proportionality (assuring that benefits are not severely overweighed by burdens and harms). Also, it would deter the physicians from pursuing the important obligation of alleviating suffering.[2]

In my view, the family's goal may be a miracle but it cannot be imposed on physicians as a goal of medical practice. Physicians can empathize with their desires and encourage their prayers. But physicians cannot do more than nature allows. Indeed, the very meaning of "miracle" depends on the premise that "the things which are impossible with men are possible with God" (Luke 18:27).

A patient is neither a collection of organs and body parts, nor a customer seeking to satisfy idiosyncratic desires. Rather, a patient (from the word "to suffer") is a person who seeks the healing (meaning "to make whole") powers of the physician. The physician's duty is to provide not merely an *effect* upon some organ, body part or physiologic function, but a *benefit* to the patient as a whole.[3] For example, the effect of JB's vasopressor medications is to maintain his blood pressure. But at this stage in the dying man's illness there is no point in keeping his blood pressure up unless it restores his consciousness and grants him, at the very least, the capacity to appreciate the effect as a benefit.

The hospital in which JB was a patient has a policy that defines medically futile treatment and outlines procedures to follow in the event of a dispute. The policy defines futile treatment as "any treatment that has no realistic chance of providing a benefit that the patient has the capacity to appreciate (as distinguished from producing physiologic effects limited to parts of the body), or merely preserves permanent unconsciousness or cannot end permanent dependence on medical care that is available only in an intensive care unit." The policy also distinguishes between "treatment" and "care," emphasizing that "although a particular treatment may be futile, care such as palliative or comfort care is never futile." This hospital policy provides specific definitional grounding and principles for the dispute resolution process involving the patient, his or her family, healthcare providers and the ethics committee, which includes lay community members. Many hospitals are developing such policies, which offer an approach to asserting a professional standard of care.[4]

The evidence suggests that if physicians request prior permission to discontinue futile treatment the courts will refuse it, but if the futile treatment is withdrawn after careful deliberation and due process, the courts will side with the physicians.[5]

The healthcare team should work with the family to make a reasonable accommodation to their needs to grieve and come to terms with the patient's dying. It is important to emphasize that "doing everything" in this case, means doing everything possible to assure that the patient undergoes a peaceful, dignified, pain-free death.

Lawrence J. Schneiderman, MD
Professor, Department of Family and Preventive Medicine
University of California, San Diego

(Continued on Page 8)

The legal column:

Informed consent for stem cell research using frozen embryos

By Dena S. Davis, JD, PhD
Professor, Cleveland-Marshall College of Law
Cleveland State University, OH

Almost every day brings fresh news about stem cells, the undifferentiated cells that appear to have the ability to evolve into many types of cells. On the scientific front, stem cells of all types — those obtained from early embryos, aborted fetuses and umbilical cord blood and other body tissues — have shown exciting potential to take on differentiated tasks. The possibilities seem infinite and could include the repair of heart and brain tissue, a cure for juvenile diabetes, the amelioration of multiple sclerosis, and more.[1]

On the legal and political front, we see a complex situation. The conflict is over the use of public monies for research with stem cells derived from very early embryos. Many scientists believe that these stem cells, being the least developed and the least "committed," have the greatest potency. The embryos under discussion are those frozen by couples in the course of infertility treatment and which they no longer wish to use. Because it is necessary to destroy the embryos to obtain the cells, many anti-abortion lawmakers are opposed to using public funds for this research. U.S. Department of Health and Human Services Secretary Tommy Thompson has not yet said whether he will back public financing of stem cell research. Letters urging the president to back stem cell research have come from members of Congress, Nobel laureates, and university presidents. But last year, 20 Republican senators sent a letter opposing the use of federal funds for studies using stem cells derived from human embryos.[2,3]

Whatever happens on the federal level, private research with embryonic stem cells will continue. Because the donors (the embryos' progenitors) are human, it is considered research with human subjects. Does this research raise issues of informed consent that are more problematic than other forms of research? In deliberations published by the American Association for the Advancement of Science,[4] the National Bioethics Advisory Commission[5] and the National Institutes of Health (NIH) itself,[6] one hears strong echoes of two other situations in which consent has been considered problematic enough to require special safeguards: consent for donation of fetal tissue following planned abortion, and consent for donation of cadaver organs for transplant.

In both cases, extra safeguards have been put into place. Women contemplating abortion can be asked to donate fetal tissue only after they have made the decision to abort so that their decision is not influenced by the possibility of donation. In the organ transplant scenario, a "wall" is put up between the people caring for the dying person and the people who ask families to consent to donation. This is to protect healthcare providers from conflict of interest, and to reassure families that their loved one's care was not negatively influenced by the possibility that he might become an organ donor.

Does consent to donation of frozen embryos for research purposes also require special safeguards? One might think so. Couples struggling with infertility are famously vulnerable, experiencing stress in almost every sphere of their lives. Further, one might argue that the sensitive status of human embryos gives society a stake in ensuring that couples donate them only after the most rigorous process of voluntary and informed consent. The proposed NIH guidelines include the following safeguards:

- There should be no inducements for donation, "monetary or otherwise."
- There should be a "clear separation" between the initial decision to create the embryos and the subsequent decision to donate excess embryos. Individuals should be approached about the possibility of donation only after they have completed their fertility efforts and determined that they have no more use for the embryos.
- Individuals should understand that they have other choices for their embryos.
- The physician responsible for treating the individuals should not be the same one who seeks to acquire embryos for research.

On the other hand, potential embryo donors are, in fact, practically ideal subjects of the consent process. People who have gone through *in vitro* fertilization (IVF) as a treatment for infertility are at least in their 20s and often older. Because in many states insurance does not cover IVF, they are likely to be middle class and reasonably well educated. By the time they have reached closure on the IVF process, either by successfully procreating or by deciding to complete their family in another manner, they are likely to be extremely well informed. Second, the decision can be made in a leisurely fashion, as embryos can be stored for an indefinite period of time. Further, their options include donation for research, donation to another infertile couple, and disposal (which can be accomplished in a dignified way with whatever rituals the couple finds comforting).

Compare this with a typical woman having an abortion and being asked to donate fetal tissue. This woman might be young, poor and uneducated, and is certainly under stress and racing the clock. Again, if we compare the situation of a family being asked to donate organs, we see people who are grieving and stressed and who must make a decision quickly. Thus, although donation of fetal tissue and of cadaver organs may superficially appear to have similarities with donation of embryos for research, in fact the differences outweigh the similarities.

Finally, people being asked to donate embryos have probably thought long and hard about the meaning of those embryos and their potential for human life. After all, the embryos were originally created for transfer to the uterus. In at least some of the families, a "brother" or "sister" of these embryos has now completed the process of transformation into personhood and is a member of the family. This

(Continued on Page 7)

Ethics and the humanities:
Wit

By Margaret Edson
Farrar, Straus and Giroux, 1999

Review by Lois LaCivita Nixon, PhD, MPH
Professor, College of Medicine
University of South Florida, Tampa

This is my playes last scene, here heavens appoint
My pilgrimages last mile; and my race
Idly, yet quickly runne, hath this last pace,
My spans last inch, my minutes last point…
—John Donne, 1609

In 1999, when Margaret Edson's play, *Wit*, opened off-Broadway, the buzz was immediate. Critics wrote of its power and intelligence; tickets sold out; the play soon moved uptown to a larger house; the unknown playwright (a kindergarten teacher!) was courted and celebrated; and the play received not only the Drama Critics Award for the Best Play and the Drama Desk Award for Outstanding Play, but also the Pulitzer Prize. The buzz continues.

Currently, the play is widely available in regional theaters and a film version with Emma Thompson has been produced by HBO. In addition, this play about the final period in a woman's life generates lively discussion in community settings, hospital ethics committees and professional meetings. Entire classes of medical students in Cleveland, Atlanta, Washington, DC, Denver, and Tampa have attended performances as well as talk-back sessions in which the dynamics of the drama are reviewed and debated.

It is not surprising that critics, the public and healthcare professionals have responded strongly to a play about a hospitalized woman struggling with end-stage cancer. In an effort to understand more about the nature of suffering, options and choices, we continue to rely on storytellers for meaning and comfort: the novelists, the poets, filmmakers, and playwrights. Following in the tradition of *King Lear, Lycidas, The Death of Ivan Ilyich, The Wasteland* and, most recently, the bestseller, *Tuesdays with Morrie*, Margaret Edson's tightly structured play provides compelling insights into the conditions of modern medicine, but, more importantly, into the complexities and needs of human beings journeying toward death.

Vivian Bearing, *Wit's* 50-year-old protagonist, is a highly respected professor of English literature whose work has centered on 17th century poet, John Donne. Accustomed to intellectual rigors associated with Donne's poetic intricacies, she is uncompromising in research and teaching. Upon admission to the hospital's oncology unit with stage 4 metastatic ovarian cancer, Bearing encounters a research unit and team that is similarly rigorous and uncompromising. In unrelated spheres of study, she and Harvey Kelekian, the physician in charge of her experimental chemotherapy program, share a passion for aggressive probing and rationality. Both have been intensely focused on their work and demonstrate a shared arrogance in their separate searches for knowledge and excellence. Neither has bothered with compassion or kindness in their pursuits and relationships.

Bearing's status is unequaled; she is at the pinnacle of her profession. Now, dressed in the hospital-issue gown, the formerly proud woman must submit to the realm of medicine. In this setting, she feels more like a piece of meat or a bug than a human being.

Her first words are to the audience in which she mimics the routinized, vapid language patterns of healthcare workers while serving to draw viewers into the world she currently inhabits:

"Hi, how are you feeling today? Great. That's just great."

For Vivian, an erudite wordsmith, the line demonstrates medicine's reductive capabilities, its power to diminish. The question is an empty formality. Because the answer, "great," completes a meaningless hospital ritual, her presentation of both question and answer establishes the situation she is in and demonstrates the unexpected transformation of language — her tool — from power to meaninglessness. A few lines later, feelings of loss are underscored when this professor of linguistic riches presents an uncharacteristically spare summary to the audience:

It is not my intention to give away the plot; but I think I die in the end. They've given me less than two hours.

The next 75 minutes cannot be reduced to such simple terms for viewers brought into the gripping drama. When the curtain does fall, an engaged but hushed audience struggles to interpret the emotional impact of the succinctly wrought play. The audience becomes her confidante, perhaps the only confidante this self-armored woman has had during her life. It is through this tragic device that her losses are revealed and her commonly human feelings are articulated.

Bearing understands her situation:

I have cancer, insidious cancer, pernicious side effects — no, the treatment has pernicious side effects. … I know all about life and death. I am, after all, a scholar of Donne's Holy Sonnets, which explore mortality in greater depth than any other body of work in the English language.

Indeed, her professional competencies are as sharply honed as those of her oncologist. Both are familiar with death, both are tough and both are unyielding. Unfortunately, while exhibiting impressive professional skills, Bearing and Kelekian are clumsy and inept in their relationships with people, especially students and patients. Only when Vivian Bearing begins to see how little room was left in her life for meaningful relationships with students and others, does she begin to recognize her human needs and also those she failed to respond to in others. □

Dialogue:

Implantable brain chips — will they change who we are?

What are your boundaries? Where do you stop and where does the world begin? If you are a violinist, your bow is already an eloquent, feeling part of you. If you drive race cars, you feel the grip of the tires on the road as if you were running barefoot. If somebody steals your eyeglasses, you are temporarily disabled as surely as if they punch you in the eye. Take away my computers and I might as well have brain damage.

The skin is an important membrane, for most purposes the natural boundary between a person and the rest of the world, but it lost its role as the edge of agency when our ancestors first began to make and use tools. Is there really that much difference between a tool you put inside your body and a tool you enclose in the palm of your hand or wear on the bridge of your nose? Most, if not all, of the conceptual issues — the ethical dilemmas and the other deep revisions in our way of life — have already been confronted time and again, in simpler versions. Implantable brain chips — if they really do become widespread (which I doubt) — will intensify problems and opportunities we are already trying to cope with. Will this intensification move us into altogether new territory? Let's consider the prospects.

Predictions about the spread of new technology have a dismal track record, so we will probably both overestimate some problems and underestimate others by a wide margin. But we should try. McGee and Maguire (*Lahey Clinic Medical Ethics Newsletter*, Winter 2001) say "these enhancements will produce major improvements in quality of life or in job performance," and although they probably didn't mean "or" to be exclusive, it may well turn to be that we will indeed have to choose. Which do we want, improved quality of life or improved job performance?

Why would anybody suppose we can't have both? Because we have already seen many instances in which improving job performance does diminish quality of life. Consider first a relatively trivial case, and then an ominous one. Thanks to global positioning systems (GPS), it is no longer possible to have the thrill of navigating your little boat across the ocean, relying on sextant and chronometer. You would be foolish to the point of criminal negligence to leave port on such a voyage without availing yourself of the best practical technology, and that technology takes the task of navigation out of your hands, routinizes it to the point where "job performance" is well nigh perfect, but job satisfaction is well nigh invisible. It's too easy a task to care about, so there is one less adventure-opportunity in the modern world. You can "rough it," locking your GPS in a box to be opened only in case of emergency, but that's an exercise in make-believe, like camping out in a theme park. The risks are all packaged.

Much the same future looms for the practice of medicine: as diagnostic technologies get better and better, the satisfactions will correspondingly evaporate. "You" caught your patient's cancer early enough to treat it successfully, but hey, all you did was order a few obligatory tests, and one came back positive. Anybody could have done it. More to the point, anybody would have been obliged to do it. A miracle of modern medicine has happened, but the "art" has been distributed throughout a huge network of technology, leaving only *relatively* routine activities for the human participants. Where there are few opportunities for heroism, for genuine, risky adventure, the quality of life is diminished. But from the patients' point of view, this is just as it should be: may all *my* medical care be as routine and risk-free — and, yes, boring — as possible!

This trend towards improved job performance with decreased grounds for satisfaction shows every sign of growing indefinitely with or without implantable brain chips. Imagine a brain chip specialized for anesthesiologists; all the outputs from all the monitoring equipment that now confront the doctor in the operating room are collected in a radio device that transmits them to the chip, for handy distribution to various appropriate cortical areas. Bad idea. Instead, just slap some earphones on the anesthesiologist and code the information about vital signs into an appropriately modulated ensemble of sounds that form a natural system that can be readily understood and internalized, and you've accomplished a superb impedance match; your anesthesiologist is optimally 'wired' without any wires in the brain. (This is not a fantasy; just such a device has been patented and will soon be in production.)

Implantation is an extreme measure that probably will never be warranted except in very special cases, where people have lost the function of some part of their nervous system. But even here, it is still not clear that implanted interfaces will be more effective than external, wearable interfaces that avail themselves of some underutilized part of the extraordinary bandwidth of the total human sensory surface. But this may change, so let's consider the range of outcomes that might confront us if implantation becomes a highly desirable course of action.

Whenever a new technology is created, it has the potential to create a new disadvantaged group: those who for whatever reason cannot avail themselves of it. When the highly visual desktop and mouse interface revolutionized human-computer interactions, a large corps of blind programmers lost their livelihoods. They could keep up with sighted programmers as long as everybody was using old-fashioned line editors which moved text around by multiple-keystroke commands, but highlight-and-drag was beyond the capacity of Braille displays to convey to their fingertips. Some activists went so far as to urge outlawing the desktop and mouse, on the grounds that it was a violation of the Americans with Disabilities Act. It is certainly *possible* (however unlikely) that some equally enhancing brain chip will be developed that can only be implanted in brains that have some currently negligible feature — a deeper-than-average central sulcus, for instance. Then we'll have created a new ethical problem: what to do about the 50 percent of the population that are ineligible for the new boon.

There is no way to avoid such problems. Any technology worth developing enhances some valued ability, and hence is almost certain to magnify some differ-

ences in ability. In some arenas of human competitive action we particularly prize equalization of ability, and in some we don't. If some violinist wants to take drugs to enhance her performance, or insists on wearing some hearing-enhancing device to improve her pitch, ensuring herself a position in the orchestra, that's her business; she may ruin her health in the quest for artistic glory (and the increasing use of beta-blockers by musicians raises some troubling issues), but we currently have no ethic that insists that she give less radically dedicated musicians a "sporting chance" to compete with her.

The use of technology in enhancing the abilities of athletes, in contrast, is a fascinating battleground for our intuitions of fairness. High-altitude training camps are OK, but achieving some of the same physiological effects by stockpiling the athlete's own blood and retransfusing it is beyond the pale — according to some people. The coach may call instructions from the sidelines (and a hearing-impaired athlete can wear a hearing aid to take advantage of this advice) but a radio-receiver tuned to the coach's transmitter is out — in some sports, but not in others.

What resources may a competitor bring to an examination or quiz? A calculator? A laptop? A cellular phone? Once again, the issue of implantation doesn't seem to me to raise *new* problems. If you can "phone a friend" to get the answer, it doesn't much matter whether your cell phone autodials from its home in your cingulate gyrus.

Very few people today know how to calculate square roots by hand, and why should they? Why memorize the list of state capitals or Tudor kings or amino acids when these can be retrieved in a few seconds from a website (or an old-fashioned multi-volume encyclopedia)? We tend to prize the skills we had to learn in school, even as they become utterly obsolete, and we tend to import the sports ethic into other arenas even when it is of dubious relevance. These heartfelt convictions may be wise or foolish, but we can't just jettison them all. We do need to agree to live by some relatively stable and mutually acknowledged set of rules, and as technology changes the background conditions, we have to revise these understandings. Equality of opportunity is an elusive goal worth striving for, however the sands may shift beneath our feet as we do so.

What, finally, of the "sinister invasions of liberty and privacy" that McGee and Maguire warn about? They are already upon us, without the need for implants. A bracelet locked on a child's or convict's ankle will do as well as an implanted chip. For that matter, a credit card or a cell phone with GPS will do as well. The prospect of implantable brain chips may *dramatize* the issues for us, but we shouldn't make the mistake of thinking that the unlikely prospects of developing such chips shows we may safely postpone decisions about them.

Daniel C. Dennett, PhD
Professor of Philosophy
Tufts University
Somerville, MA

McGee and Maguire's reply

Professor Dennett's intriguing response to our paper on "Implantable brain chips: ethical and policy issues," claims that brain chips add nothing new to the ethical concerns raised by technology in general, and that "there is no way to avoid such problems." Essentially, he seems to assume that the endeavor of reflecting upon and controlling technologies is futile. Our paper did not claim that brain chips will raise uniquely new ethical issues; rather our point is that there are ethical problems inherent in the proper human uses of technologies, that brain chips are a likely future technology, and that it is both possible and necessary to formulate policies and regulations which will mitigate their effects.

There are differences between harnessing the power of fire and harnessing that of nuclear energy, between the use of carrier pigeons and the direct transmission of thoughts via wireless brain waves. That these differences are ones of degree rather than of kind, does not imply that they are insignificant. A "tool" such as implantable brain chips collapses the traditional separation between the tool and the subject using the tool, and necessitates mechanisms to ensure that it is a tool that one can choose not to use. Concerns about autonomy, privacy and the just allocation of benefits are not ethical issues that will suddenly become real with the advent of brain chips; rather the technology will put new forms of stress on privacy, autonomy and justice, and the task of applied ethics is to look for practical ethical responses to such posited problems. It is more than probable that brain chips will be used since they will very significantly reduce the power required and provide for a highly efficient system. To adopt a fatalistic attitude towards this development is irresponsible, and will leave the decision making in the hands of technocrats, corporations and governments. □

Ellen M. McGee, PhD
Director, The Long Island Center for Ethics
Long Island University — CW Post,
Brookville, NY

Gerald Q. Maguire, Jr., PhD
Royal Institute of Technology,
Kista, Sweden

Legal *(Continued from Page 4)*

should reassure those who worry about thoughtless disposition of embryos. RESOLVE, the support group for people facing infertility, has come out in support of federally funded stem cell research.

In sum, if it becomes possible to use public money for stem cell research, the NIH rules that would apply are, if anything, overprotective of potential donors. In the private sphere, the standard protections for informed consent that pertain to any research setting are sufficient to ensure that couples are making the decision whether or not to donate their spare embryos in ways that are consonant with their values. □

[1] Kaji EH, Leiden JM. Gene and stem cell therapies. *JAMA* 2001;285:545–50.

[2] Southwick R. 95 Lawmakers ask Bush to allow federal aid for stem-cell studies. *Chronicle of Higher Education* March 30, 2001.

[3] Southwick R. College presidents back stem-cell research. *Chronicle of Higher Education* April 6, 2001.

[4] American Association for the Advancement of Science, Institute for Civil Society. *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research.* Washington, DC:AAAS, 1999.

[5] American Association for the Advancement of Science, Institute for Civil Society. *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research.* Washington, DC:AAAS, 1999.

[6] *Ethical Issues in Human Stem Cell Research, Executive Summary.* Rockville, MD: National Bioethics Advisory Commission, 1999. <www.bioethics.gov>.

Genetically modified *(Continued from Page 2)*

I would argue that the truth lies in between these two views. Clearly, it is a mistake to think that a sense of moral repugnance or anxiety is sufficient to end debate. However, it is not irrelevant to the debate either. Analysis of these moral concerns and using them as a way to frame issues may be useful in a way that a simple risk-benefit analysis will miss. For example, an important source of concern is not merely risk, but such questions as, who is exposed to the risk? Who has the power to make decisions about that risk? Is the scientific community accountable to the public? These and other questions must be addressed as central to debates over genetically modified organisms. The sources of moral concern must be explored and addressed if we are to move forward with a technology that offers both promise and pitfall. □

[1] Cho MK, Magnus D, Caplan AL, McGee D. Policy forum: genetics. Ethical considerations in synthesizing a minimal genome. *Science* 1999;286:2087–90.

[2] Pollan M. Playing God. *The NY Times Magazine*, Oct. 25, 1998.

[3] Gaskell G, Bauer MW, Durant J, Allum NC. Worlds apart? The reception of genetically modified foods in Europe and the U.S. *Science* 1999;285:384–7.

[4] Kass LR, Wilson JQ. *The Ethics of Human Cloning*. Washington, DC:AEI Press, 1998.

[5] Pence GE. *Who's Afraid of Human Cloning?* Lanham, MD:Rowman and Littlefield, 1998.

Ethicist *(Continued from Page 3)*

Outcome: The family was given a date and time at which anyone who wished could be present with JB when all life support would be withdrawn. This date gave the family sufficient time to seek transfer of the patient or court intervention — which they chose not to do.

All treatments and monitors were withdrawn and JB died peacefully in the presence of his family. □

[1] Schneiderman LJ, Jecker NS. *Wrong Medicine: Doctors, Patients and Futile Treatment.* Baltimore, MD: Johns Hopkins University Press, 1995.

[2] Schneiderman LJ, Faber-Langendoen K, Jecker NS. Beyond futility to an ethic of care. *Am J Med* 1994;96:110–114.

[3] Schneiderman LJ. The futility debate: effective versus beneficial intervention. *JAGS* 1994;42:883–886.

[4] Schneiderman LJ, Capron AM. How can hospital futility policies contribute to establishing standards of practice? *Cambridge Q Healthcare Ethics* 2000;9:524–31.

[5] Johnson SH, Gibbons VP, Goldner JA, Wiener RL, Eaton D. Legal and institutional policy responses to medical futility. *AHA Journal of Health Law* 1997;30:21–47.

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
Managing Editor

David M. Gould, Esq.
Legal Editor

Gloria G. Barsamian, MA
Circulation Manager

Editorial Board
Bernard Gert, PhD
Diane M. Palac, MD
Paul L. Romain, MD
James A. Russell, DO
Thomas J. Prendergast, MD

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 CLINIC

Lahey CLINIC
Medical Ethics NEWSLETTER

41 Mall Road
Burlington, MA 01805

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