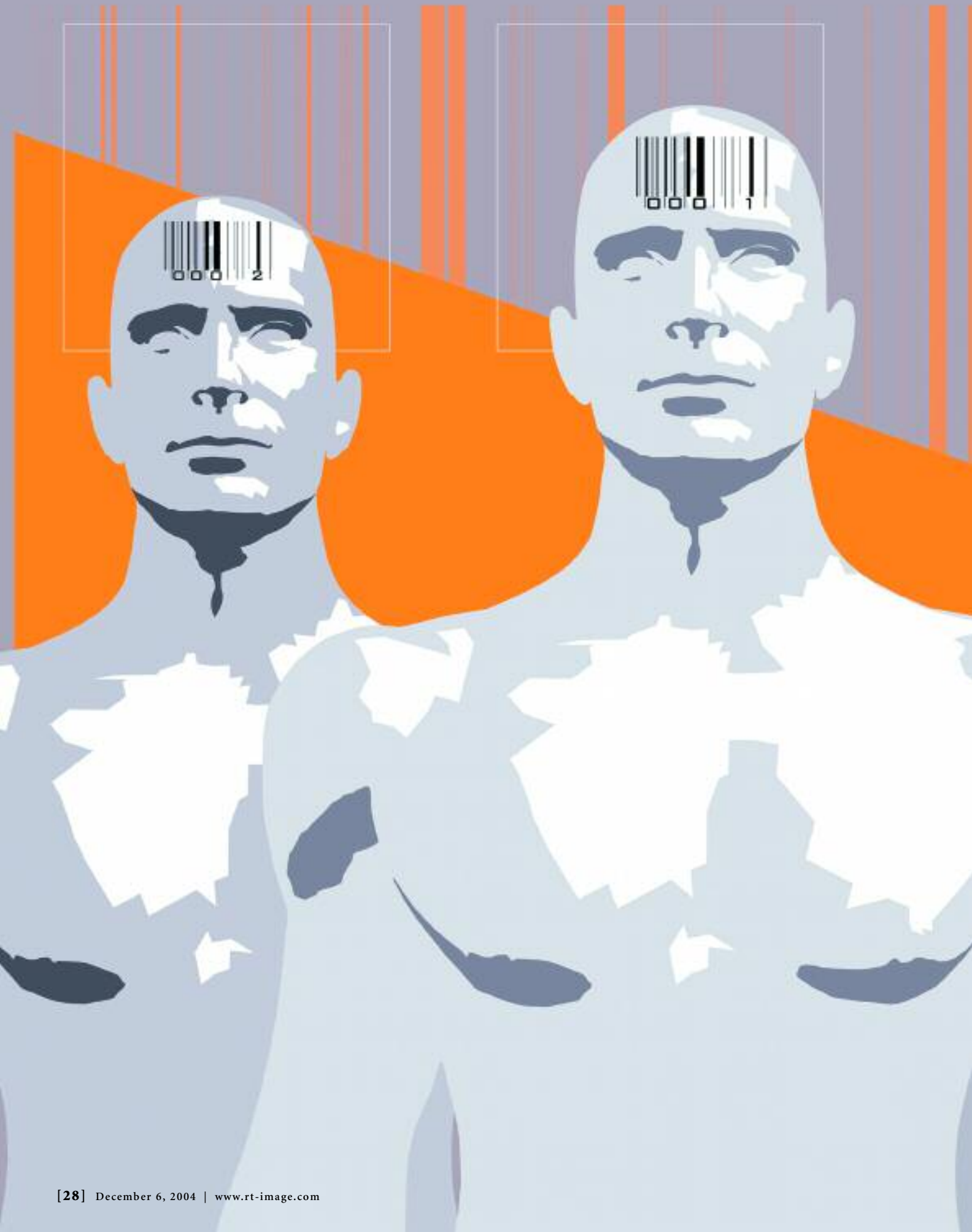
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Beyond Human

Genetics, eugenics and the moral challenge of the 21st century

BY JEREMY KUHAR

Moron.

A single word was stamped in bold, black ink across the top of the file. To the Commonwealth of Massachusetts, Freddie Boyce was just another one of the "morons" warehoused at the Walter E. Fernald State School for the Feeble-minded, located just outside Boston in Waltham, Mass.

Freddie arrived at Fernald in 1949 after the last of his foster parents died. He never knew his father and barely knew his mother. After taking a primitive version of an IQ test, he was determined to be mentally insufficient and labeled a moron – just one of many scientific terms given to kids with slight mental capacities. He was given a school uniform and put to work. It didn't matter that Freddie would be considered normal by today's standards. He was simply poor, uneducated and had nowhere else to go. So they locked him away.

"We thought for a long time that we belonged there, that we were not part of the species," Boyce said 50 years later, recalling his days at Fernald in an interview with "60 Minutes." "We thought that we were some kind of people that weren't supposed to be born."

It would take nearly 50 years for him to be able to cope with the torment and anguish he endured at Fernald. He was physically abused by the attendants, mentally abused by administrators and even unwittingly fed radioactive oatmeal as part of a bogus science experiment conducted by researchers at the Massachusetts Institute of Technology. There were plenty of nightmarish stories, but it was being labeled a moron that left the biggest scar – a single word stamped on the heart and soul of an utterly normal 7-year-old orphan.

21ST CENTURY CHALLENGE

Freddie Boyce and the other children at Fernald didn't know it, but they were victims of America's eugenic era, locked away by bureaucrats to prevent the "genetically inferior" from reproducing and adding to America's collective gene pool. Long-running, but almost forgotten, the practice of eugenics was perhaps our nation's darkest hour. According to Edwin Black, author of *War Against the Weak* (Four Walls Eight Windows, 2003), during the first half of the 20th century, American corporate philanthropy joined with prestigious academic universities to create the pseudoscience of eugenics. The goal: to create a superior, genetically engineered race. Now more than a half-century later, the uniqueness of human dignity is once again at stake.

Although the eugenic era has faded, Boyce's story is more important today than ever before. Recent strides in biotechnology raise the hope for technological progress, but they also raise fundamental moral questions about our humanity. As radiologists employ cutting-edge genetic research to detect, diagnose and treat a wide variety of diseases, suddenly we're faced with a perilous scenario. What if this genetic information was somehow used to discriminate the "genetically inferior" like the children of Fernald?

"Can't happen? Think again," says Nigel Cameron, PhD, president of the Institute on Biotechnology and the Human Future, a bioethics think tank at Chicago-Kent College of Law.

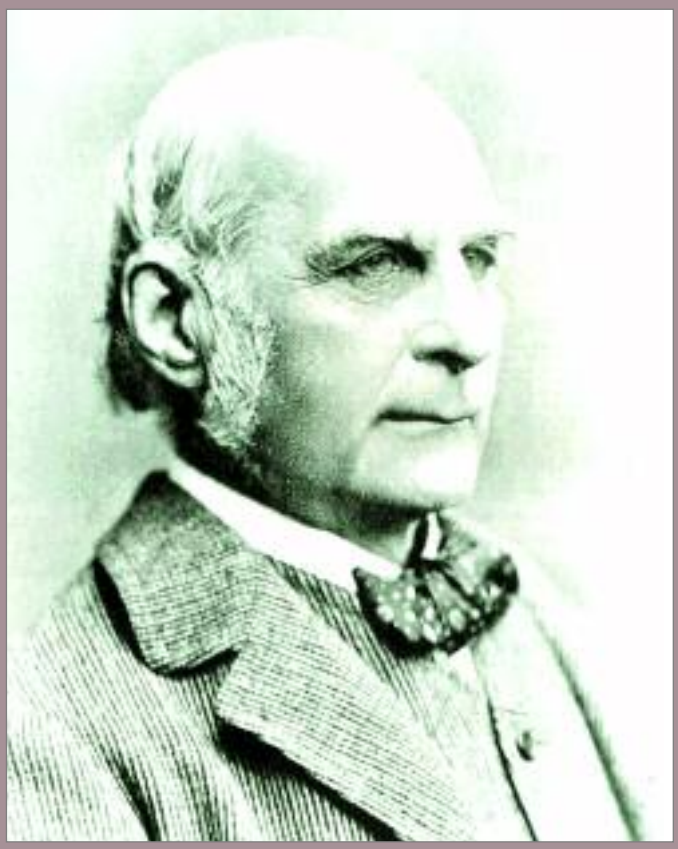
"Many people, including insurers, employers and schools, have incentives to discriminate based on genetic makeup. Employers and insurers could reject healthy applicants just because their genes may show they have a statistically higher chance of getting cancer. And schools could simply choose to admit only those whose genes suggest they'll have a better chance to succeed."

In fact, genetic discrimination is already happening on a smaller scale, he adds, citing a case of an Iowa railway worker who filed a workers' compensation claim. When he was asked for a blood sample, the company sent the tube out for a secret genetic screening. If the results showed a predisposition for carpal tunnel, they would have a defense against the worker's claims that the job left him debilitated. They would then have no obligation to pay their employee because the worker's genes caused the injuries, not the job. The worker eventually found out and filed suit against the company for invading his privacy.

Cameron says that genetic discrimination, like other forms of discrimination, is difficult to identify and measure. "So as the volume of genetic information grows, it is important for individuals and society to decide not only who should be allowed access to genetic information, but how that information may be used," he says.

And that's just the tip of the ethics iceberg. As if the bioethical decisions facing radiology aren't complicated enough, they're just the first phase of what he calls the moral challenge of the 21st century. As genetic technology proliferates and combines with nanotechnology, information technology and a whole host of other "ologies," many experts believe that this convergence of hi-tech sciences will eventually be used to bioengineer a "superior" human species or several species, known as techno sapiens or posthumans.

It sounds far-fetched, Cameron admits, but the technologies needed to bioengineer a new species are already being developed in research labs across the country.



http://galton.org

Charles Darwin's cousin Sir Francis Galton coined the term "eugenics" and was the leading proponent of racial improvement from 1860 to 1890. He wrote many books in which he claimed that "human mental abilities and personality traits, no less than the plant and animal traits described by Darwin, were essentially inherited." Ultimately, these findings sparked the formative years of the eugenics movement, which called for methods of improving the biological makeup of the human species through selective parenthood. Galton would even go so far as to advocate human breeding restrictions to curtail the breeding of the feeble-minded.

So what exactly is a posthuman?

"In the posthuman, there are no essential differences, or absolute demarcations, between bodily existence and computer simulation, cybernetic mechanism and biological organism, robot technology and human goals," writes Katherine Hayles, PhD, professor of English at the University of California, Los Angeles in her book *How We Became Posthuman* (University of Chicago, 1999). She concludes her book with a clear description of what's at stake. "Humans can either go gently into that good night, joining the dinosaurs as a species that once ruled the earth but is now obsolete, or hang on for a while longer by becoming machines themselves. In either case … the age of the human is drawing to a close."

The question remains: Which direction will we go?

"There are groups of very smart philosophers and researchers who truly believe that blending artificial intelligence with bioengineered human intelligence is the logical and irrevocable future of mankind," says Cameron. "Whether they call it techno sapiens, transhumanists or posthumans, the idea they are putting forth is that the convergence of biotechnology, nanotechnology

American Philosophical Society

(Top) Between 1900 and 1940 local and state eugenics organizations conducted massive public relations campaigns intended to promote big families for those who had good genes. However, for those who were deemed unfit, public policy suggested they be institutionalized, even sterilized. The most frightening aspect of eugenics, says Edwin Black, author of *War Against the Weak*, is that at one point in time, eugenics was considered a respectable science. (Bottom) The ultimate expression of positive eugenics was the ideal American family, which produced strong, healthy, intelligent children. Such families competed in "Fitter Family" competitions. The winners of the small family class at the 1925 Eastern States Expositions in West Springfield, Mass., are shown in this photo.

and information technology (IT) should be used to enhance humans, to make them better, to the point that the very essence of the human condition is drastically changed forever."

We often scoff at the sci-fi notion of techno humans or half-robot, half-man superhumans, but what was once science fiction is now science fact, says Douglas Mulhall, author of the book *Our Molecular Future* (Prometheus Books, 2002). The truth, he says, is that we are not that far away from an IT enhanced, bioengineered superhuman. "In some ways, we have already begun the transition. Prosthetics have been transplanted into nervous systems so amputees can move robotic arms and legs. Computers have been implanted into neural pathways, via retinal implants that allow blind people to see," says Mulhall. "It's just a matter of connecting those chips via a Bluetooth wireless connection and man and machine are one."

Nick Bostrom, PhD, professor of philosophy at Oxford University in the United Kingdom and founder of the non-profit think tank the World Transhumanist Foundation, echoes a similar thought. "It's only a matter of time before technology changes the essence of being human," he says. Instead of trying to suppress the technology, he suggests embracing the movement to help guide its direction in an ethical manner, "to ensure the transformation beyond human is performed in a meaningful way."

So just how far away are these technologies? To Bostrom, it's clear that the ability to change many fundamental parameters of the human condition will be developed within a few decades. However, one look around the exhibit hall at the scientific assembly of the Radiological Society of North America (RSNA) and the immediate impression is that these changes may be even sooner.

The first steps of this futuristic world were on display last week at RSNA 2004. In GE Healthcare's Technology Pavilion, visitors were treated to exhibits of what healthcare will look like in the year 2015. The research and development on display included new, targeted diagnostics, as well as information technologies solutions and imaging equipment that will enable physicians to predict, diagnose, inform and treat disease earlier than ever before.

Armed with a new generation of diagnostics, researchers will be able to identify what they call "genetic fingerprints" of specific diseases that predict the course of how those diseases are likely to develop and progress. Gene-based technologies being developed also will help physicians understand a patient's individual genetic profile to predict their likelihood of developing certain diseases and enable them to carry out proactive monitoring and overall healthcare management.

Advanced diagnostic imaging systems and contrast agents will produce high resolution structural and functional images of living tissue, enabling physicians to identify disease and its specific location. For example, GE Healthcare is developing novel molecular agents that image the process of angiogenesis, the growth of new blood vessels. By honing in on this process, they hope to help physicians more accurately and less invasively diagnose and treat a variety of diseases such as cancer, cardiovascular disease and wound healing.

GE is also working to understand disease at the molecular level to ascertain a patient's ability to metabolize specific drugs, enabling physicians to tailor treatment to an individual patient. The growing understanding of disease will yield more targeted and more effective therapies to rule out ineffective drugs. From side effects to outcomes, each patient's individual response to treatment will be more accurately predicted.

"We are leveraging our knowledge of molecular biology, electrical engineering, nanotechnology and digitization to drive advances in medical diagnostics," says Sir William Castell, CEO of GE Healthcare and vice chairman of GE. "These advances will shift today's hospital-centric model of healthcare based on finding and treating disease late, to a more patient-centric model in which we hope to predict and prevent disease."

It's hard to argue with technology when it clearly has the potential to revolutionize healthcare. However, opponents argue that it's just a matter of time before researchers will want to switch from predicting and diagnosing to preventive measures through genetic bioengineering, says Mulhall. "With 99 percent of the human genome mapped, it's only a matter of time before someone will use that information to discriminate against the 'genetically inferior' or create humans completely resistant to disease. This is the dilemma we face. Just how far do we go?"

To most of us, the idea of a posthuman or new human species is downright ludicrous. But as, Bostrom argues, if it has even a small chance of happening, we must begin to consider the consequences. "By historical standards, things are now happening fast, and it seems fairly probable that molecular manufacturing and superintelligent machines will be developed in this century," he says.

This scenario is both scary and exciting, he continues, adding that possible outcomes range from extinction to unimaginably wonderful lives. "We could eventually become ageless creatures with vastly improved intellectual, emotional and moral capacities that would enable us to have experiences that are impossible with our current neurobiological limitations. Human nature as we currently know it is not an eternally fixed constant, but, I believe, an early draft of a work-in-progress."

In this debate, the range of opinions stretches from those who fully support merging artificial and human intelligence to those who adamantly advocate worldwide bans on all transhuman related research activities.

Of primary concern for Cameron are the dangers of biotechnology and its ability to destroy the uniqueness of human dignity. "As C.S. Lewis warned a half-century ago in his essay *The Abolition of Man*, the new capacities of biotechnology give us power over ourselves and our own nature," says Cameron. "But such power will always tend to turn us into commodities that have been manufactured. As we develop powers to make inheritable changes in human nature, we become controllers of every future generation."

This isn't to say that genetic based-medicine is entirely bad, he continues. Recent advances in biotechnology have brought about wonderful discoveries. And he believes it would be a great error to think that all biotechnology is inherently evil or that all biomedical research is unethical. "We recognize and applaud ethical research," says Cameron. "However, not all technological breakthroughs are so clearly ethical."

National Debate

Despite the often-heated arguments over how we should use this technology to enhance our lives, one important point both sides can agree on is that the discussion of the future of the human race must move to the forefront of American conversation. And as members of the scientific and medical communities, all radiology professionals owe it to themselves to become informed. The implications for us all are simply too big to ignore, says Mulhall.

"Simply pushing the issues aside will not get us anywhere," he says. "For example, President Bush's current administration is making a grave mistake in blocking the development of new stem cell lines. By this administration refusing to discuss the stem cell issue, the bulk of the research has moved overseas. China, Korea, Japan, India and a handful of other countries are zooming right past the United States in any areas of research where the administration is intending to impose a moral agenda on science."

The truth, he adds, is that regardless of whether stem cell research is morally right or wrong, the approach is ineffective in restricting research. If someone wants to impose a moral agenda, they are going to have to find a different way to stop the research, he says.

Cameron agrees. Instead of drawing lines in the sand and playing politics, he advocates bringing all sides of the debate together to engage in a meaningful discussion. "The only way to address these key questions is to ask the hard questions early," says Cameron. "Hearing the hard questions early allows the key thought leaders on both sides of the debate the opportunity to share ideas and discuss policy."

Not only will the public be more likely to embrace technology previously viewed as threatening, says Cameron, but there's another added benefit for the business community and the companies who have invested vast amounts of money into the research and development of this technology. "You will actually create a market that will be accepting of your technology. I've attended many meetings on this technology and the businesses are already asking these questions. They want to address the ethical issues early so that down the line these questions will already have been raised and addressed and we will have a market for their product."

Early discussion of the ethical issues is key. He points to the "fiasco" that recently occurred in Europe as an example of mistake we can all learn from. "There is almost zero market for bioengineered agricultural products because of the incompetent way the technology was launched. Environmental activists were up in arms," says Cameron, "because they were never consulted. They viewed the new technology as a danger. The end result was a market that refused the AgBio products."

Now that $4 billion has been given to fund nanotechnology and its related biosciences through the National Nanotechnology Initiative, Cameron wants to know if the Bush administration is going to encourage the discussion of the hard questions so that we can produce products driven by this technology that respect the human condition, as well as safety issues. "Unless we critique these technologies," says Cameron, "not only will human dignity suffer but the market will suffer as well. As consumers of genetic-based medicine and other possible applications, we'll oppose the research if we do not participate in the discussion. And a fiasco similar to the European AgBio debacle will begin to develop."

A good example of the way different sides of a political argument spectrum were able to come together is Proposition 71, the California Stem Cell Research and Cures Initiative. "You had the Catholic Church and the feminists working together, forming their policies. They were probably holding their noses at each other, but they were working together on the political issue. They were sharing a conversation about our national policy and how we should move forward through this new day and age," Cameron says.

Whether or not a discussion will lead to a compromise remains to be seen. Some scholars are pessimistic about the possibility of reaching a compromise. H. Tristram Engelhardt, PhD, professor of philosophy at Houston's Rice University, says that the two sides in the stem cell debate, for example, are "moral strangers" whose basic beliefs will never permit agreement on policy. Others point out that current President's Council on Bioethics' policy recommendations, which forbid embryo stem cell research on one hand but allow production of unused embryos during in vitro fertilization on the other, are already political compromises.

And still when it's all said and done, what truly may determine the course of the next decade of scientific research is what makes the world go 'round: money. There's almost $4 billion dollars being invested over the next four years and that, says Cameron, proves nanotechnology, biotechnology and IT are ready to break out from the basic research stage. The National Cancer Institute announced on Sept. 13 a new $144.3 million, five-year initiative to develop and apply nanotechnology to cancer. Federal funding for nanotechnology research and development has increased six-fold, from $116 million in 1997 to an estimated $961 million in 2004. And corporations are following suit. GE gobbled up Amersham plc to form the $14 billion bioscience powerhouse GE Healthcare, positioning themselves to be a major player in the bioscience driven future.

Pretty soon all types of applications will be showering down upon us, as where the money flows, research and discovery are not far behind.

Role of Radiology

So how do we decide the limits of human enhancement? Current technologies are already pushing the limits. And behind lab walls, the next level of research is underway. There are techno enthusiasts who want unlimited ability to enhance the human race as far as technology allows. There are those who argue that a complete ban on related research is negligent. Others say we are going too far too fast. These new questions need to be addressed now. They will have a profound effect on what it means to be human.

In an age of uncertainty, one thing remains clear. The only way to determine the right course is to bring together prominent stakeholders in this debate – from the left and the right, those who would welcome the prospect of a "posthuman" future, to critics who want to ensure that human integrity is safeguarded and the good retain center stage. And as radiology professionals, those who may be on the front line of bioscience integration, we must take a leading role in the ethical debate.

"It is by having this conversation," says Cameron, "and having it in on an international scale, that we can best encourage understanding of the potential significance of these technologies and ensure the primacy of human dignity in their development."

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History Lesson

Many bioethics experts suggest that the best way to make informed decisions is to learn from past mistakes. And many would agree that the American eugenics movement would be a good place to begin the discussion of the bioscience research currently underway in radiology.

In the 1900s, hundreds of thousands of children deemed "feeble-minded" were locked behind the walls of state institutions, separated from the rest of the society for the sole purpose of "weeding out" the genetically inferior from our national gene pool. The movement, called eugenics, asserted that human traits like intelligence, character and morality were biologically rooted and therefore could be improved through selective breeding.

Americans were told that we could get rid of all diseases, lower crime rates and increase our nation's wealth if we kept certain genetically inferior people from reproducing. The theories were embraced by our nation's leading research institutions and blindly pursued by the federal government and local bureaucrats. Exhibits were set up at state fairs across the country. The message: Eugenics was good for America and good for the human race.

What was eugenics? It was the widely adopted practice of improving human qualities through selective breeding. However, what started as a genuine attempt to improve our society degenerated into a racist, systematic effort to eradicate "inferior" Americans. "So-called 'defective' family trees were identified and subjected to legislated sterilization programs," says Edwin Black, author of the investigative book *War of the Weak* (Four Walls Eight Windows, 2003). "They went after everyone: poor people, immigrants, brown-haired white people, African Americans, Eastern European Jews, orphans, you name it. Really, it was anyone classified outside the superior genetic lines drawn up by American raceologists."

But the most important point for us to grasp, continues Black, is that this battle to wipe out "genetic misfits" was fought not by armies with guns, rather "it was carried out by esteemed professors, elite universities, wealthy industrialists and government officials. Through the veil of a fraudulent science called eugenics, they continued with the single pernicious purpose: to create a superior race," he says.

As radiology continues to push the edge of genetic-based medicine, all radiology professionals must take a primary role in the discussion of ethics in the practice of our medicine.

Michael D'Antonio

Freddie Boyce and the other boys of the Fernald School for the Feeble-minded were victims of America's eugenics era. Pictured here in a photo around the 1950s, the boys are hard at work at the school producing goods for the Commonwealth of Massachusetts.