THE NEW ATLANTIS
A JOURNAL OF TECHNOLOGY & SOCIETY

The Real Meaning of Genetics

Eric Cohen

With a subject as large and as profound as modern genetics, we face a major question from the start about how to approach it. We could take a *scientific approach*, examining the use of information technology in genomic research, or the latest advances in identifying certain genetic mutations, or the transfer of genetic knowledge into useful medical technologies. We could take a *social scientific approach*, seeking to understand the economic incentives that drive the genetic research agenda, or surveying public attitudes toward genetic testing, or documenting the use of reproductive genetic technology according to socioeconomic class. We could take a *public safety approach*, reviewing different genetic tests and therapies for safety and efficacy, and ensuring that sound regulatory procedures are in place to protect and inform vulnerable patients undergoing gene therapy trials. As we think about the genetic future, all of these approaches are valuable, but none of them is sufficient.

The reason we care so much about the new genetics is that we sense that this area of science will touch on the deepest matters of human life—such as how we have children, how we experience freedom, and how we face sickness and death. Like no other area of modern science and technology, genetics inspires both dreams and nightmares about the human future with equal passion: the dream of perfect babies, the nightmare of genetic tyranny. But as usual, the dream and the nightmare are not the best guides to understanding the real meaning of genetics. We need a more sober approach—one that confronts the real ethical dilemmas we face, without constructing such a monstrous image of the future that our gravest warnings are ignored like the bioethics boy who cried wolf.

Possibility and Prediction

In thinking about the new genetics, we seem to commit two errors at once: worrying too much too early and worrying too little too late. For decades, scientists and science-fiction writers—and it is sometimes hard to tell the difference—have predicted the coming of genetic engineering: some with

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fear and loathing, some with anticipatory glee. But when the gradual pace of technological change does not seem as wonderful as the dream or as terrible as the nightmare, we get used to our new powers all too readily. Profound change quickly seems prosaic, because we measure it against the world we imagined instead of the world we truly have. Our technological advances—including those that require overriding existing moral boundaries—quickly seem insufficient, because the human desire for perfect control and perfect happiness is insatiable.

Of course, sometimes we face the opposite problem: Scientists assure us that today's breakthrough will not lead to tomorrow's nightmare. They tell us that what we want (like cures for disease) is just over the horizon, but that what we fear (like human cloning) is technologically impossible. The case of human cloning is indeed instructive, revealing the dangers of both over-prediction and under-prediction. So permit me a brief historical digression, but a digression with a point.

In the 1970s, as the first human embryos were being produced outside the human body, many critics treated *in vitro* fertilization and human cloning as equally pregnant developments, with genetic engineering lurking not far behind. James Watson testified before the United States Congress in 1971, declaring that we must pass laws about cloning now before it is too late. In one sense, perhaps, the oracles were right: Even if human cloning did not come as fast as they expected, it is coming and probably coming soon. But because we worried so much more about human cloning even then, test-tube babies came to seem prosaic very quickly, in part because they were not clones and in part because the babies themselves were such a blessing. We barely paused to consider the strangeness of originating human life in the laboratory; of beholding, with human eyes, our own human origins; of suspending nascent human life in the freezer; of further separating procreation from sex. Of course, IVF has been a great gift for many infertile couples. It has answered the biblical Hannah's cry, and fulfilled time and again the longing most individuals and couples possess to have a child of their own, flesh of their own flesh. But it has also created strange new prospects, including the novel possibility of giving birth to another couple's child—flesh *not* of my flesh, you might say—and the possibility of picking-and-choosing human embryos for life or death based on their genetic characteristics. It has also left us the tragic question of deciding what we owe the thousands of embryos now left-over in freezers—a dilemma with no satisfying moral answer.

But this is only the first part of the cloning story. Fast-forward now to the 1980s. By then, IVF had become normal, while many leading scientists

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assured the world that mammals could never be cloned. Ian Wilmut and his team in Scotland proved them all wrong with the birth of Dolly in 1996, and something similar seems to be happening now with primate and human cloning. In 2002, Gerald Schatten, a cloning researcher at the University of Pittsburgh, said "primate cloning, including human cloning, will not be in our lifetimes." By 2003, he was saying that "given enough time and materials, we may discover how to make it work." And by 2005, Schatten and his South Korean colleagues had reliably cloned human embryos to the blastocyst stage, the very biological moment when they might be implanted to initiate a pregnancy. In all likelihood, the age of human reproductive cloning is not far off, even if the age of full-blown genetic engineering may never come.

Looking at where the science of genetics is heading, we must beware the twin vices of over-prediction and under-prediction. Over-prediction risks blinding us to the significance of present realities, by inebriating us with distant dreams and distant nightmares. Under-prediction risks blinding us to where today's technological breakthroughs may lead, both for better and for worse. Prediction requires the right kind of caution—caution about letting our imaginations run wild, and caution about letting science proceed without limits, because we falsely assume that it is always innocent and always will be. To think clearly, therefore, we must put aside the grand dreams and great nightmares of the genetic future to consider the moral meaning of the genetic present—the meaning of what we can do now and why we do it. And we need to explore what these new genetic possibilities might mean for how we live, what we value, and how we treat one another.

Humanly speaking, the new genetics seems to have five dimensions or meanings: (1) genetics as a route to self-understanding, a way of knowing ourselves; (2) genetics as a route to new medical therapies, a way of curing ourselves; (3) genetics as a potential tool for human re-engineering, a prospect I find far-fetched; (4) genetics as a means of knowing something about our biological destiny, about our health and sickness in the future; and (5) genetics as a tool for screening the traits of the next generation, for choosing some lives and rejecting others. I want to explore each of these five dimensions in turn—beginning with the hunger for self-understanding.

Genetic Self-Understanding

The first reason for engaging in modern genetics is simply man's desire to know himself, a desire that nearly all of us share, if not in equal degrees. Alone among the animals, human beings possess the capacity and the

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drive to look upon ourselves as objects of inquiry. We study ourselves because we are not content simply being ourselves. We are not satisfied living immediately in nature like the other animals do. Food and sex alone do not satiate us. We do not accept the given world as it is; we also seek to uncover its meaning and structure. Modern biology, of course, is only one avenue of self-understanding, one way of asking questions. But it is an especially powerful and prominent way of seeking self-knowledge in the modern age. Instead of asking who we are by exploring how humans live, the biologist asks who we are by examining the mechanics of human life. Genetics fits perfectly within this vision: it seems to offer us a code for life; it promises to shed empirical light on our place in nature; it claims to tell us something reliable about our *human* design, our *pre-human* origins, and our *post-human* fate.

But it is also true that the more we learn about genetics, the more we seem to confront the limits as well as the significance of genetic explanation. As the cell biologist Lenny Moss put it (in a passage quoted in these pages by Steve Talbott):

> Once upon a time it was believed that something called "genes" were integral units, that each specified a piece of phenotype, that the phenotype as a whole was the result of the sum of these units, and that evolutionary change was the result of new changes created by random mutation and differential survival. Once upon a time it was believed that the chromosomal location of genes was irrelevant, that DNA was the citadel of stability, that DNA which didn't code for proteins was biological "junk," and that coding DNA included, as it were, its own instructions for use. Once upon a time it would have stood to reason that the complexity of an organism would be proportional to the number of its unique genetic units.

But in fact, the triumph of modern genetics has also meant the humbling of modern genetics. Big hypotheses now seem to require revision and greater measure. And in many ways, we are probably relieved that genetics does not tell us everything we need to know about ourselves. For human beings, this means that we are still more free than any genetic account of being human would leave us. And for young scientists, this means that life's mystery is still as great as ever; today's earnest graduate student can surpass even Watson and Crick in making the crucial breakthrough that might reveal our humanity once and for all—that might give us "the secret of life," as Crick declared when he burst into the British pub in 1953.

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Even as we are relieved at discovering the limits of genetic determinism, however, our hunger for genetic explanation remains strong. Disease is also a threat to our freedom, after all, and we still hope that genetics might help us conquer that mortal threat. We still hope that genetics is the secret of disease, if not the secret of life.

Genetic Therapy

And this leads me to the second dimension of the new genetics: the search for medical cures. Modern science, unlike ancient science, does not rest on the foundation of curiosity alone. It seeks to conquer nature, not simply to understand nature's meaning. And while man may be the only truly curious animal, his curiosity is not his only guiding passion. He also seeks health and he certainly fears death. Like other animals, human beings seek comfort and survival. But unlike other animals, we possess the capacity to pursue comfort and survival through the systematic application of reason. Modern science, especially modern biology, promises the "relief of man's estate," in Francis Bacon's famous phrase, in return for the right to explore nature without limits. Descartes skillfully negotiated this bargain centuries ago, and I quote here a passage much cited by those interested in the origins of modern science:

> So soon as I had acquired some general notions concerning Physics … they caused me to see that it is possible to attain knowledge which is very useful for life, and that, instead of that speculative philosophy which is found in the Schools, we may find a practical philosophy by means of which, knowing the force and the action of fire, water, air, the stars, heaven, and all the other bodies that environ us, as distinctly as we know the different crafts of our artisans, we can in the same way employ them in all those uses to which they are adapted, and thus render ourselves as the masters and possessors of nature.

Not surprisingly, the "nature" we most seek to "master" is our own. We seek to conquer human disease, and perhaps even to make death itself a series of conquerable diseases. It is apparently part of our genetic code to revolt against our genetic fate.

Of course, the "speculative philosophy" of the Schools that Descartes sought to leave behind was religious metaphysics—which is to say, the search for man's place in the cosmological whole and before God. The new science and the old religion thus seem to present us with two different ways of revolting against our biological fate: The religious believer seeks

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such revolt *beyond nature* in God, by looking beyond our genetic deficiencies to the hope of eternal salvation. The scientist seeks such revolt *through nature* in science, by understanding nature's mishaps (or mutations) so that we might correct them. The unknowable God, if you believe He really exists, promises better long-term results; He "cures" us forever, but only after death. The empirical scientist, if you give him enough public funding, provides better short-term results; he cures us now, but only for a while. This does not mean that science and religion are enemies: religious people are often great scientists, and great scientists are often deeply religious. But it does suggest that the cure-seeking scientist lives on the narrow ridge between holiness and rebellion: He imitates the old God by healing the sick; or he supplants the old God by believing that he can eradicate all sickness, by working within nature rather than looking beyond it.

Genetics, in this sense, is simply a new frontier in the long ascent of modern medicine. It aims to repair broken genes or correct disease-causing mutations by direct intervention. And it aims to use our growing understanding of the human genome to diagnose and treat human disease with greater precision.

But it turns out that most diseases are more complicated than genetics alone, and that markers for identifying and predicting a given disease do not always or easily translate into usable knowledge about the disease's causation. The capacity to fix genes with perfect precision and without side effects is also proving remarkably difficult. Already, there have been some high-profile examples of gene-therapy trials going terribly wrong, and the field now proceeds with perhaps a more befitting caution. Over time, of course, there is little doubt that our genetic knowledge will improve modern medicine and thus prove a great blessing to us all. But there also seems little doubt that the new genetics will probably not be the therapeutic panacea that many once hoped, and which many scientists and policymakers offered as a central justification for the human genome project. Biological knowledge and biological control are simply not the same, even when it comes to curing disease, and most certainly when it comes to so-called genetic engineering.

Genetic Design

This brings me to the third dimension of the new genetics: the much-discussed prospect of designing our descendants—a prospect I find unlikely. In the reproductive context, I think the real dilemma may involve

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picking and choosing human embryos for implantation based on the genetic characteristics that nature gave them. But this is significantly different from designing human beings with genotypes entirely of our own creation. By focusing so much energy on the dream and the nightmare of genetic engineering, we risk treating the real-life possibilities of genetic control as less profound than they really are. Yet again: we worry too much too early or too little too late.

To be sure, it may be possible to engineer various genetic monstrosities—like a human version of the monkeys with jellyfish genes that glow in the dark. Perhaps some modern-day Frankenstein will create fetuses with primordial wings; or children with seven fingers; or human beings that are part male and part female by design. If human life is seen as a mere canvas, and if the biologist sees himself as an artist thriving on "transgression," then genetic engineering is a real problem. And sadly, there is little doubt that someone, somewhere, will attempt such terrible experiments, and may succeed in producing at least embryonic or fetal monsters. But I also have little doubt that most democratic societies will pass laws that prohibit the biological equivalent of postmodern art. Precisely because it is so grotesque, such monster-making is not our most serious ethical problem.

Democratic societies, after all, do not seek the monstrous; we seek the useful. And the worst abuses of biotechnology may come in trying to make the seemingly monstrous dimensions of life disappear in the name of mercy, by screening and aborting those with handicaps or deformities that we believe make their lives not worth living. There will always be knaves who reject society's laws and principles and engage in monstrous acts for their own sake. But the real challenge is to consider those uses of genetic knowledge and genetic choice that are both technically feasible (as science, not art) and that seem to run with rather than against the grain of liberal society. It is those potential abuses that have some utilitarian justification—such as improving life, or ending suffering, or guaranteeing every child a healthy genome, or expanding reproductive freedom—that we must confront most squarely.

But since many people worry so much about genetic engineering, I would be remiss to ignore it entirely. So let me offer a brief critique. The most tempting reason to engage in genetic engineering is to assert new kinds of control over our offspring, and to design children with certain desirable *human* attributes: children with high IQs, perfect pitch, beautiful appearance, remarkable strength, amazing speed, and photographic memories. Some might even seek to design human offspring with better-

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than-human attributes. But these scenarios strike me as technically unlikely and humanly misguided. Technically, I doubt whether we will ever gain, or gain soon, the sophistication to engineer certain human traits *de novo*, and I doubt whether the traits we seek to engineer are so clearly rooted in a definable genetic pattern that we can deliberately replicate or improve the pattern. At the very least, I believe the project of trying to find such patterns and implement such designs would involve so many grotesque failures that the backlash would be swift.

More deeply, I doubt that we can actually design a *better* human being—even as a genetic thought experiment. If the goal of the designer is human *excellence* or better-than-human excellence, he must begin with an idea of excellence itself. And here, I think, we face two insurmountable hurdles: First, I doubt that we can improve upon nature when it comes to making a better musician, or artist, or scientist. It is hard to imagine a composer better than Mozart or a playwright better than Shakespeare. In seeking to maximize some human trait by genetic manipulation, we will most likely deform other crucial traits, and thus deform the excellent human wholes that nature so mysteriously and so remarkably supplies. And if we seek, say, to make faster men to run our races, have we really created better men—or just biological machines? Cars move faster than men; pitching machines throw harder than pitchers—but neither invention is better than human; they are merely sub-human things. (This problem is explored in great detail in *Beyond Therapy*, a report produced by the President's Council on Bioethics.) And even if we could make as many Mozarts as we like, do we really serve the cause of human excellence by making that excellence so common? I doubt it.

The second major barrier to the genetic engineering project is the fact that superior talent is not the only form of human excellence. Many of the most admirable human beings do not live lives dominated by measurable achievement, but lives of fidelity, or charity, or love, or courage. Perhaps there are important genetic predispositions to such traits of character, but good genes are rarely enough to make good men, even if bad genes sometimes make individuals so psychologically impaired (or chemically imbalanced) that virtue is beyond their reach. Moreover, I suspect that even replicating these good genetic predispositions will be beyond the engineer's reach, because they involve so many biological factors that go beyond mere genetics. Even if our technology improved, I doubt that we can engineer more virtuous offspring—which is the only real measure of whether genetic engineering would make human life truly better.

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All that said, the one form of "genetic engineering" that does demand our attention is the very real prospect of human reproductive cloning—a way of controlling the genetic make-up of our offspring with great precision, by copying the genetic make-up of someone already here. The ethical and social significance of human cloning is profound, involving a deep violation of the relationship between parent and child. But technically, cloning is remarkably simple compared to other imagined forms of genetic engineering. It does not involve manipulating the interlocking pieces of the human genome, but the wholesale replication of an existing genotype. It is more like copying a great novel already written than writing a great novel from scratch.

And it is this technical ease, in fact, that makes cloning a genuine worry, not simply a distracting dream or nightmare. Cloning involves a perverse form of self-love, by imposing our own genomes on our children. It robs new life of an open-ended future, and it forces the young clone to live always and forever in the shadow of his elder genetic twin—in the shadow of both his past accomplishments and past failures. In the end, human cloning may prove a test case of our capacity to limit the dehumanizing uses of biotechnology, and our capacity to defend those human goods—like the family—that make human life truly human.

Genetic Foreknowledge

But if most forms of genetic engineering, beyond cloning, are probably not in the offing, this hardly means that the new genetics is socially and ethically insignificant. Certainly not. What it means is that we need to pay much closer attention to the human meaning of *genetic knowledge* itself—both how we use it and what it does to us once we possess it. And this brings me to the fourth dimension of the new genetics: the meaning of gaining partial foreknowledge about our biological fate, and especially the meaning of knowing bad things (or good things) about our biological future.

Of course, to be self-aware at all is to have some foreknowledge of our mortal destiny: We know that death will one day take us; we know that natural disasters, or terrible accidents, or vicious attacks could make this day our last day; we know that some mysterious ailment could strike us without warning. Those of us who eat the wrong foods and spend too much time at our desks know that heart problems and clogged arteries may lie in our future; even without sophisticated genetic tests, we know about the presence of hereditary diseases in our families; and we all know that time will eventually win its final victory, whether at age 70, or 80, or 90, or 100.

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And yet, most of us live our day-to-day lives without focusing too much on our own mortality. For better and for worse, we do not live each day as if it could be our own last; we do not make the fact of death a dominant reality in our everyday lives. When a loved one dies or some tragedy strikes, we are perhaps reminded of our mortal condition; we might imagine our children throwing dirt into our graves. But the immediacy of life quickly returns, and we live again, for a while, as if the horizon of the future were very long, if not indefinite.

Strangely, modern individuals are both more obsessed with death and less aware of death than their less-modern forebears. We are obsessed with trying to avoid death through better diets and better medicine, yet we are less aware of death because it rarely strikes us in untimely ways, at least compared to the omnipresence of death in the lives of our ancestors. In modern societies, most people die after living full lives, not from mass plagues, or mass killings, or infant mortality.

In an essay on the meaning of mortality, the philosopher Hans Jonas quotes the following passage from Psalms: "So teach us to number our days, That we may get us a heart of wisdom." His point is not primarily religious but existential. If we lived as if tomorrow were forever, we would lack the urgency to live boldly and love deeply. And if we believed that this life would last forever, even the sweetest things would become routine.

But in the age of genetic testing, the instruction to "number our days" takes on new meaning, since these tests may allow us—or force us—to number them with increasing precision. Today, there are numerous deadly diseases that we can diagnose through genetic testing with absolute or near-absolute certainty, and long before we experience any visible symptoms. For some of these diseases—like Huntington's—there is no cure; the diagnosis is a death sentence, giving the likely age of onset, the likely period of decline, and the likely age of death if nothing else kills first. For other diseases—like breast cancer—genetic tests can offer a highly reliable if not perfect indication of a person's susceptibility to the disease, with potential treatments ranging from preemptive surgery to remove one's breasts and ovaries to intense monitoring to detect the coming cancer as early as possible.

But does this genetic foreknowledge make life better or worse? Is there a case for genetic ignorance? At what age and under what circumstances should people know their genetic fate? These are hard moral questions with no easy answers.

In those situations like Huntington's where the diagnosis is clear and there is no cure, genetic self-knowledge seems like both a blessing and a

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curse. It is a blessing, because it might lead individuals to an uncommon wisdom about the preciousness of life; it might move them to live without wasting time, because they know just how short their time really is. And yet, such foreknowledge must also seem like a curse; the permanent presence of looming death might make living seem worthless; there are too many projects they know they can never finish and too many ambitions they know they can never fulfill. Their genetic death sentence may come to feel like a living death, with no escape except pharmacology or suicide.

In those situations where some therapeutic preemption is possible, like for those who test positive for the breast cancer mutation, the young often face drastic and wrenching decisions: Is the greater chance of longer life worth living with the scars of mastectomy, or living without the possibility of bearing children of one's own? Is it really better to have the knowledge that makes such a tragic choice necessary, rather than the ignorance that would allow us to live without being so haunted until the disease really comes?

Right now, the number of diseases we can test for genetically is somewhat limited, and many of these tests offer clear positive or negative diagnoses. But what may be coming is a world of imperfect knowledge about terrible possibilities—with a battery of tests that give greater and lesser probabilities of getting certain diseases, at certain times, compared to the general population. All of our human fears will be sharpened; our paranoia made more precise; our anxieties given a genetic scorecard. What good is this knowledge to us, especially when the power to diagnose will come long before the power to cure—the so-called "diagnostic-therapeutic gap"? And yet, will we be able to resist this new form of high-tech astrology? Will it teach us to number our days and make us wise? Or will it make life seem like a short trip through a genetic minefield—by forcing us to confront every morning the ways we might die?

Genetic Choice

These types of genetic foreknowledge take on new meaning when we move to the reproductive sphere, and when the burden is not simply living with knowledge of one's own potential fate, but deciding whether such knowledge is a morally compelling reason to abort an affected fetus or discard an affected embryo. And this leads us to the final dimension of the new genetics: the use of genetic knowledge to make reproductive decisions, to decide between life worth living and life unworthy of life.

For a long time, we have worried about the so-called "enhancement problem," and feared that some people would use genetic technology to

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get an unfair advantage for their offspring. But this, I believe, is the wrong worry. The real danger is that the limitless pursuit of equal results—the desire to give everyone a mutation-free life, and thus an equal chance at the pursuit of happiness—will actually undermine our belief in the intrinsic equality of all persons. The pursuit of genetic equality will lead to the age of genetic discrimination. And in some ways, it already has.

Of course, if we could avoid conceiving a sick or disabled child, we would do so. And if we could safely cure Tay-Sachs or Down syndrome during pregnancy or *in vitro*, we would do so. But once conception has taken place, and in cases where there is no cure, we are left with the decision to accept or reject a life in-progress—a life that is real enough to us that we can evaluate and pass judgment on its genetic characteristics. With the arrival of pre-implantation genetic diagnosis (PGD), we may face a radical transformation of assisted reproduction—a transformation made more significant by the rising numbers of women and families turning to IVF to have children. In this new world, genetic testing would become a standard part of IVF, and the tested embryos would be divided into different classes: those doomed to suffer killer diseases like Tay-Sachs would be separated from those that are not; those doomed to suffer disabilities like Down syndrome would be separated from those that are not; those prone to suffer late-onset diseases like breast cancer would be separated from those that are not.

By making reproduction into a process of division by class, we transform the welcoming attitude of unconditional love into a eugenic attitude of conditional acceptance. Of course, we would do this in the name of compassion, or mercy, or equality. We seek to give our children healthy genetic equipment, and to spare those who would suffer by "nipping them in the bud." But the pursuit of genetic equality requires a radical program of genetic discrimination. Whatever we might think about the moral status of the early embryos tested in PGD, they are certainly not nothing. They are real organisms, with the same genetic identity as embryos that they would have through life if those who created them in the first place decided to let them live.

Seen clearly, the real danger of the genetic age is not that the "gene-rich" will outpace the "gene-poor"; it is that the pursuit of genetic equality will erode our willingness to treat those who are genetically unequal as humanly equal. We will replace the hard work of human love for the disabled with a false compassion that simply weeds out the unfit. It is hard to see how the equal dignity of persons with Down syndrome is served by

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treating Down syndrome as a legitimate reason to abort. And it is hard to see how parents will experience pregnancy with any equanimity or joy if they have a full genetic read-out of their embryo or fetus, and must decide whether the mutation for breast cancer, or Parkinson's, or Alzheimer's disease is reason enough to abort and try again. This is the moral paradox at the heart of genetic control: In seeking an existence without misery or imperfection, we may make ourselves more miserable and imperfect; and we may even do miserable things in the name of a falsified mercy. And in the very act of bringing new life into the world, we will already be thinking about how our future child will die.

Beyond Genetics

Without question, the advance of modern genetics is one of the great achievements of our time, an example of the creative and truth-seeking spirit at the heart of our humanity. But too often, we easily assume that the progress of science is identical to the progress of man. The truth, as always, is much more complicated. Many men and women of the past were superior in virtue to us now, and many scientific discoveries of the present and future will prove a mixed blessing, and sometimes even a curse.

The new genetics will deliver us many goods but also confront us with many burdens. We will need to make choices, and those choices will require philosophical judgments about "better" and "worse," not only scientific judgments about "possible" and "impossible." We will need to think especially about the goods in life that are higher than health—the goods that make being healthy worthwhile. And this is the very task that modern genetics is least equipped to handle.

We will also need to challenge the lazy assumption that genetic knowledge is simply "neutral," with a meaning that depends entirely on "how we use it." For this, too, is much too simple. New knowledge is never neutral; it is always a way of being in the world, a way of seeing our condition, a way of seeking truth, happiness, and virtue. Genetics is no exception, and genetic knowledge will never eradicate or eliminate those perplexities of life that require the kind of wisdom that no material science can ever offer.

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