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SPEECH

THE REVOLUTION IN HUMAN GENETICS: IMPLICATIONS FOR HUMAN SOCIETIES

PROFESSOR HENRY T. GREELY*

I. INTRODUCTION

I would like to try to compress two semesters of seminars into a very short period of time. It is going to be a difficult task—I am reminded of a comedy group that performs all of Shakespeare in thirty minutes. I am different from that group in two ways: I am not funny and I don't have thirty minutes. I will, however, try to cover as many of the issues as I can, because I think all of us—as lawyers and future

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lawyers, as legislators, as physicians, and as citizens—need to be thinking about the effects of the revolution in human genetics on our human society.

Specifically, I want to cover the possible social consequences of six major areas touched by the new genetics: (1) social effects of medical advances, (2) issues of identity, (3) predicting the future, (4) manipulating genomes, (5) ownership and control, and (6) changed understandings.[1] Before that, I must stress two overriding themes. First, the issues about human genetics in human society are not really new.[2] They have arisen in the past with respect to other technologies and other changes—genetics, for the most part, just puts the same issues in a slightly different context. Second, human genetics is both extremely powerful and sometimes relatively weak.[3] We all must avoid assuming, as I think the public too often does, that genetic effects are always powerful. Sometimes they are—sometimes they are not.

II. MEDICAL ADVANCES

Let us start with the social and legal consequences of some of the medical implications of genetics research. The potentially wonderful medical benefits coming from increased research in human genetics affect not only what we think of as genetic diseases, but also other diseases that have mild genetic components, and still other diseases that are not "caused" at all by genetic variations but for which genes play a role in either the disease progress or the disease treatment. The last two classes of disease have really been driving this revolution. Scientists are interested in genetics largely for its own sake, but the legislatures, pharmaceutical companies, venture capitalists, and individual investors who have been paying for this research are interested in products that will improve human life (while improving bottom lines) through the treatment and prevention of disease. I do not think we are going to live to be two hundred years old or even that our children are going to live to be two hundred years old, but genetics research will contribute significantly to an increase in life span and a decrease in misery during life. That is great news, which is usually overlooked by people like me who look at the ethical, legal, and social implications of genetics—we tend to be a gloomy lot.

But every silver lining has a gray cloud wrapped around it. Law students in the audience, ask yourselves this: If my generation lives to be ninety-five, who is going to be paying for our Social Security? Not just you, but your children, and our Medicare and our nursing homes. What if we can cure the physical diseases of old

1. *See* Henry T. Greely, *Legal, Ethical, and Social Issues in Human Genome Research*, 27 ANN. REV. ANTHROPOLOGY 473 (1998) [hereinafter *Legal, Ethical, and Social Issues*] (discussing these areas in greater detail along with the implications of using DNA to uncover the past); Henry T. Greely, *Ethical Issues in the "New" Genetics*, INTERNATIONAL ENCYCLOPEDIA OF THE SOCIAL AND BEHAVIORAL SCIENCES (3d ed. forthcoming 2001).

2. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 473.

3. *See id.*

age before we cure some of the mental deterioration and we end up with a country with tens of millions of demented nonagenarians and centenarians? Even before we get to that stage, when we have exciting new—and usually expensive—drugs, who is going to get these drugs in a country where approximately forty-four million Americans have no health insurance?[4] This is not so much a problem in the rest of the rich world, which is civilized enough to make sure that all of its citizens get health insurance, but we have not become that civilized yet. Even if we do adopt universal coverage and decide that people with low cost health insurance or people without health insurance will have access to these drugs, what about the ninety-five percent of the human species that lives outside of the United States? Consider the people in sub-Saharan Africa who are dying of HIV right now and who are causing great tension in international intellectual property law by seeking (and sometimes getting) deep discounts for life saving therapies?[5] Effective new therapies can be wonderful things, but they will bring a set of problems that we are going to have to deal with, as a result of the genetic revolution.

III. IDENTITY

The basic issues with respect to the forensic use of DNA in court are now resolved. Judges and juries throughout the country understand that DNA evidence is very powerful—except in the O.J. Simpson case. But even the O.J. Simpson case is a nice example that no matter how powerful the technology, the police still have to prove the traditional issues of physical evidence: the origin of the DNA sample, that the sample was not contaminated, that it was not tampered with, and so on. In the area of forensic identification, we have now moved to a second type of DNA identification that does not look at known suspects and known crime scenes, but actually involves checking the DNA from a crime scene against a database of criminals, people who have been accused of crimes, and people who have been arrested. Every state now has a DNA database and repository for forensic purposes.[6]

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4. As of 1998, forty-four million Americans were uninsured. THE KAISER COMM'N ON MEDICAID AND THE UNINSURED, UNINSURED IN AMERICA: A CHART BOOK 12 (2000), *available at* http.//www.kff.org.

5. Mark Schoofs & Michael Walaholz, *First Accord to Cut Prices is Made with Merck, Bristol Myers and Glaxo*, WALL ST. J., Oct. 24, 2000, at A3.

6. *See* ALA. CODE § 36-18-20 (Supp. 1998); ALASKA STAT. ANN. § 44.41.035 (Michie 1998); ARIZ. REV. STAT. ANN. § 31-281 (West 1989), § 13-4438 (Supp. 1998); ARK CODE. ANN. §§ 12-12-1105 to -1106 (Michie 1999); CAL. PENAL CODE § 295 (Supp. 1999); COLO. REV. STAT. ANN. § 17-2-201(5)(g)(I) (2000); CONN. GEN. STAT. ANN. § 54-102g (Supp. 1999); DEL. CODE ANN. tit. 29 § 4713 (1997); FLA. STAT. ANN. § 943.325 (West 1997); GA. CODE ANN. § 24-4-60 (1995); HAW. REV. STAT. § 706-603 (1993 & Supp. 1999); IDAHO CODE § 19-5505 (Michie 1997 & Supp. 1999); 725 ILL. COMP. STAT. ANN. 207/45 (West 1993 & Supp. 2000); IND. CODE § 10-1-9-8 (1982); IOWA CODE ANN. §§ 13.10 (West 1995); IOWA ADMIN. CODE r. 61-8.1(13) (1998); KAN. STAT. ANN. § 21-2511 (1995 & Supp. 1998); KY. REV. STAT. ANN. § 17.170 (Banks-Baldwin 1999); LA. REV. STAT. ANN. §§ 15:605, 606 (Supp. 1999); ME. REV. STAT. ANN. tit. 25, § 1571 (West 1998 & Supp. 1998); MD. ANN. CODE art. 88B, § 12A (1995 & Supp. 1997); MASS. GEN. LAWS ANN. ch. 22E, § 2 (Supp. 1999);

But there is not a lot of agreement on whose DNA should be in it. In some states the database includes only convicted sex offenders,[7] in other states it includes all convicted felons,[8] and in the United Kingdom, for example, it includes anybody who has been arrested.[9] Where are we going with this? We are all potential subjects of this database. Is that a good thing or a bad thing? I have been fingerprinted a number of times for various purposes, including for admission to the bar. My fingerprints are on file in many places. Is DNA different?

Two important issues here will have to be resolved, probably within the next ten years. First, how broad should the collections be? Should they include just convicted people, or all arrested people? Should they include the entire population? These collections are not only useful for solving crimes but also for identification of remains, and, if samples are taken early enough, for identification of stolen or kidnaped children. Second, what kind of information should be kept? Information about the thirteen markers considered the "DNA fingerprint"[10] does not tell us much about an individual.[11] It does not tell us anything about a person's medical risks, height, sex, or anything else.[12] But if we keep the actual physical samples, and not just the analysis of a few meaningless markers, then potentially we can know a lot

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MICH. COMP. LAWS ANN. § 750.520m (West 1991 & Supp. 1999); MINN. STAT. ANN. §§ 609.3461, 299C.155 (Supp. 1999); MISS. CODE ANN. § 45-33-15 (West 1999); MO. ANN. STAT. §§ 650.050, .055 (Supp. 1999); MONT. CODE ANN. § 44-6-102 (1999); NEB. REV. STAT. § 29-4104 (Supp. 1998); NEV. REV. STAT. § 176.0913 (1998); N.H. REV. STAT. ANN. § 632-A:21 (Supp. 1999); N.J. STAT. ANN. § 53:1-20.21 (Supp. 1999); N.M. STAT. ANN. § 29-16-6 (Michie 1997); N.Y. EXEC. LAW § 995-c (McKinney 1996); N.C. GEN. STAT. § 15A-266.4, .5 (1997); N.D. CENT. CODE § 31-13-05 (1996); OHIO REV. CODE ANN. § 2901.07 (West 1994 & Supp. 1999); OKLA. STAT. ANN. tit. 57, § 588 (Supp. 1999); *id.* tit. 74, § 150.27 (West 1995 & Supp. 1999); OR. REV. STAT. §§ 181.085, 137.076 (1997); PA. STAT. ANN. tit. 35, § 7651.301 (Supp. 1999); R.I. GEN. LAWS § 12-1.5-4 (Supp. 1998); S.C. CODE ANN. § 23-3-610 (Supp. 1997); S.D. CODIFIED LAWS § 23-5-14 (1998); TENN. CODE ANN. § 38-6-113 (1997), § 40-35-321 (1997 & Supp. 1999); TEX. GOV'T. CODE ANN. § 411.142 (Vernon 1998); UTAH CODE ANN. § 53-10-406 (Supp. 1999); VT. STAT. ANN. tit. 20, § 1933 (1997 & Supp. 1999); VA. CODE ANN. § 19.2 - 310.2 (Supp. 1999); WASH. REV. CODE ANN. § 43.43.752 (West 1998); W. VA. CODE ANN. § 15-2B-4 (1995 & Supp. 1999); WIS. STAT. ANN. §§ 165.76-77, 973.047 (West 1998); WYO. STAT. ANN. § 7-19-402 (Michie 1999).

7. *See* WASH. REV. CODE ANN. § 43.43.754 (West Supp. 1995) (requiring all sex offenders and individuals convicted of certain violent offenses to register DNA); FLA. STAT. ANN. § 943.325 (West Supp. 1995) (requiring all persons convicted of sex offenses, murder, and manslaughter to register DNA); MO. ANN. STAT. § 650.050 (Supp. 1994) (requiring all persons convicted of sex offenses, murder, and manslaughter to register DNA).

8. *See* VA. CODE ANN. § 19.2 -310.2 (Michie 1990 & Supp. 1994); W.VA. CODE ANN. § 15-2-24a (Michie Supp. 1994).

9. *See* Jean E. McEwen, *DNA Data Banks, in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 231, 235-36 (Mark A. Rothstein ed., 1997) [hereinafter GENETIC SECRETS]; *see also* Robert W. Schumacher II, *Expanding New York's DNA Database: The Future of Law Enforcement*, 26 FORDHAM URB. L.J. 1635, 1647 (1999).

10. *See* Russ Hoyle, *The FBI's National Database*, 16 NATURE BIOTECHNOLOGY 987, 987 (1998) ("DNA law . . . sharply limits DNA identification technology to 13 basic probes that can isolate genetic characteristics, but are unable to provide fuller details of identity.").

11. *See id.*

12. *See id.*

about those people. Watch this issue of DNA collections. They can be a powerful tool in criminal justice, especially for solving cold cases—cases where you have some physical evidence but no suspect—but they also raise powerful issues about privacy.[13]

IV. PREDICTING THE FUTURE

The power of DNA to predict the future is the area that concerns people the most. There are five subparts to this issue.

A. Prenatal or Early Postnatal Situations[14]

The use of genetic testing in prenatal or early postnatal situations is one way DNA predicts the future. Postnatal tests, some of which are required by law in every state in the union,[15] identify genetic disease like phenylketonuria (PKU)[16] or galactosemia.[17] We require these tests because babies identified with the genetic defects can receive medical interventions to limit, or eliminate, the diseases' ill effects.

Prenatal genetic tests can predict many diseases, most untreatable. Should we require that testing? When should we require hospitals and doctors to *offer* that testing to individuals? My state, California, requires that all pregnant women be offered a test called Maternal Serum Alpha-Fetoprotein testing.[18] That test shows whether a fetus is at heightened risk for Downs Syndrome, Spina Bifida, Anencephaly, and a number of other severe conditions.[19] By requiring that it be offered, we encourage people to take the test. By encouraging people to take the

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13. For a discussion about the privacy issue, see generally GENETIC SECRETS, *supra* note 9; Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 WAKE FOREST L. REV. 767 (1999).

14. *Legal, Ethical, and Social Issues*, *supra* note 1, at 479.

15. *See* Scott Burris & Lawrence O. Gostin, *Genetic Screening from a Public Health Perspective: Some Lessons from the HIV Experience*, *in* GENETIC SECRETS, *supra* note 9, at 140 (stating phenylketonuria screening is mandatory in almost every state); *see also* Laura N. Sinai, et al., *Phenylketonuria Screening: Effect of Early Newborn Discharge*, 96 PEDIATRICS 605, 607 (1995) ("Every state requires metabolic screening for a variety of genetic diseases, including phenylketonuria ('PKU') before an infant is discharged from the hospital.").

16. Phenylketonuria is a congenital disease that produces brain damage resulting in severe mental retardation. Diets low in phenylalanine can prevent this retardation. *See* STEDMAN'S MEDICAL DICTIONARY: FIFTH UNABRIDGED LAWYER'S EDITION 1072 (1982).

17. Galactosemia is a congenital disease caused by an unborn error of galactose metabolism. Galactosemia can cause nutritional failure, hepatosplenomegaly with cirrhosis, cataracts, mental retardation, galactosuria, aminoaciduria, and albuminuria, but manifestations can regress or disappear if galactose is removed from the diet. *See id.* at 570.

18. 17 CAL. CODE REGS. tit. 17, § 6527 (2001).

19. LYNN B. JORDE ET AL., MEDICAL GENETICS 223-25 (1995).

test, we encourage people, probably, to abort fetuses who test positive.[20] Is that something we as a society want to do?[21]

B. Testing for Adult Onset Diseases[22]

The second subpart of using genetic testing is predicting the future health of people who are already alive and old enough to make their own decisions through genetic tests for adult onset diseases. Adult onset testing exists for diseases like Huntington's disease,[23] for the heightened susceptibility to breast and ovarian cancers that come from mutations in BRCA1 and BRCA2 genes,[24] and for a number of other genetic conditions. We can say something about your future health by doing a test of your genes.

On the other hand, we usually cannot say much. There are not very many diseases where DNA can predict your future perfectly. There are a few, such as Huntington's disease, a very nasty, untreatable, lingering—and rare—neurological disorder.[25] As far as we know, if you have one copy of the disease-linked version of the gene that leads to Huntington's disease, the only way to avoid getting the disease is to die first from something else.[26] It is what geneticists call one hundred percent penetrant—one hundred percent of the people with the genotype get the disease.[27]

Most genetic diseases are not like that. Many can be treated. My nearsightedness, which is quite extreme, is partially genetic. My glasses work fine; many people now get surgery for several thousand dollars that they think works even better than my glasses. There are also many diseases which we know have a genetic component to them, but the genetic variations do not lead to disease one hundred percent—or zero percent—of the time. Such strong associations are (relatively) easy to find. The effects of genetic variations on disease usually are going to be more subtle. They may raise your risk of a disease from eight percent to eleven percent. Or maybe they reduce your risk from eight percent to five percent. What do we make of that information? Why do we want those predictions?

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20. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 479.

21. *See id.*

22. *Id.* at 480; *see also* Henry T. Greely, *Genetic Testing for Cancer Susceptibility: Challenges for Creators of Practice Guidelines*, 11 ONCOLOGY 171 (Nov. 1997); Barbara A. Koenig et al., *PGES Recommendations on Genetic Testing for Breast Cancer Susceptibility*, 7 J. WOMEN'S HEALTH 531-45 (June 1998); Laura McConnell et al., *Genetic Testing and Alzheimer Disease: PGES Recommendations*, 3 GENETIC TESTING 3-12 (May 1999).

23. *See* Nat'l Soc'y of Genetic Counselors, *Predisposition Genetic Testing for Late-Onset Disorder in Adults*, 278 JAMA 1217, 1217 (1997).

24. *See* Mary-Claire King et al., *Inherited Breast and Ovarian Cancer: What are the Risks? What are the Choices?*, 269 JAMA 1975, 1975-85 (1993).

25. *See* THE DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 149 (4th ed. 1994).

26. *See* HUNTINGTON SHELDON, BOYD'S INTRODUCTION TO THE STUDY OF DISEASES 276 (11th ed. 1992).

27. *See id.*

These are questions we are all going to face as patients. When do you want to be tested and why? The answer will be a balance that will vary with each individual and each kind of test. If there is good medical intervention for the disease, the test is a lot more attractive. With colon cancer, good medical interventions, particularly increased monitoring, now exist. There are interventions for breast cancer, but their value is more questionable. Huntington's disease has no interventions. That makes a difference.

There are also the risks. People might worry about insurance or employment discrimination.[28] Those are the risks most talked about. Most states have taken steps in a haphazard, patchwork way to try to combat the risks of health insurance discrimination,[29] but they have not done so with life insurance.[30] And some states have taken steps with respect to employment discrimination.[31] I believe most people exaggerate the risks of health insurance discrimination because most of us who are fortunate enough to have health insurance get it in ways that do not allow medical underwriting. Our insurers do not get to pick and choose whom to cover because most of us get insurance through our employers, medicare, or medicaid, none of whom do medical underwriting. Only ten to fifteen percent of the insurance market is medically underwritten.[32] If I left my tenured position with a solvent university and became a freelance writer, I would be in that position as well. For one—and for most of us—this kind of discrimination is a potential threat. It is not a very real threat yet, but it is good that people are trying to take action with respect to it. But there are other costs to adult onset testing which are much less frequently talked about that I think are often more important than the insurance issue.

People in families with a history of genetic disease tell me that genetic testing often causes discord within the family.[33] One sister wants to get tested for BRCA1

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28. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 481-83; *see also* Henry T. Greely, *"Genotype Discrimination": The Complex Case for Some Legislative Protection*, PENN. L. REV. (forthcoming 2001); Henry T. Greely, *Health Insurance, Employment Discrimination, and the Genetics Revolution in* THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT (Daniel Kevles & Leroy Hood eds., Harvard University Press 1992).

29. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 481-83; *see also* William F. Mulholland, II & Ami S. Jaeger, Comment, *Genetic Privacy and Discrimination, A Survey of State Legislation*, 39 JURIMETRICS J. 317 (1999).

30. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 481-83; Mulholland & Jaeger, *supra* note 29, at 317.

31. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 481-83; Mulholland & Jaeger, *supra* note 29, at 317.

32. *See* Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 KY. L. J. 503, 534, 555 (1996-97). "Medically underwritten" insurance policies base the price, scope and availability of the health insurance on the health of the applicant. William M. Sage & Peter J. Hammer, *Competing on Quality of Care: The Need to Develop a Competition Policy for Health Care Markets*, 32 U. MICH. J.L. REFORM 1069, 1097-98 (1999).

33. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 480; *see also* Lori B. Andrews, *Gen-Etiquette: Genetic Information, Family Relationships, and Adoption*, *in* GENETIC SECRETS, *supra* note 9 at 255-80; King et al., *supra* note 24, at 1977; Nat'l Soc. of Genetic Counselors, *supra* note 23, at

or BRCA2, the other sister doesn't. They fight, they are unhappy. The mother feels guilty when she learns that she has passed on a gene for increased Alzheimer's risk to her children. And I think in some ways, issues surrounding genetic testing are toughest in marriages. If you take a genetic test and discover you are at high risk for Huntington's disease or early onset Alzheimer's disease or breast cancer, do you tell your spouse? If you do tell your spouse, what is going to happen? Is he or she going to leave you? Well, that would be a little dramatic. Is he or she going to become emotionally distant from you? Perhaps. The familial consequences of genetic testing are a real cost for a lot of people and an issue that is not talked about very much.

The other serious cost that is often over-looked involves the personal, psychological consequences for some people. Most genetic research has been done with Huntington's disease, which is one hundred percent penetrant, has a one hundred percent death rate, and no treatment. And the good news is, on average, most people who take the test are about as happy or unhappy a year later as they were before, whether they test positive or negative. But that is an average and the average conceals extremes. Some people go to pieces and some people feel better. As you might expect, often times people who do not have the Huntington's disease gene feel better. People who test positive feel worse, but not always. Sometimes people who test positive feel better. Why? Maybe because they are no longer uncertain. Sometimes people who test negative—they won't get the disease—feel much worse. Why? A sense of guilt, perhaps, that all of their relatives have had this and they are spared somehow?[34] Nancy Wexler,[35] the psychologist who was largely responsible for the effort that led to the finding of the gene, tells about a thirty-four year old man who had always assumed he was going to get Huntington's disease (his father had it) but finally decided to get tested at the age of thirty-four. The test was negative, but he suffered an emotional breakdown anyway. Why? He had dropped out of three colleges, declared bankruptcy twice, had never had a long term relationship, and had been arrested on white collar criminal charges. He had always assumed he only had thirty-five years to live. At thirty-four he found that he had another forty years to live—and that he had ruined them.[36]

The deeper point here is that the psychological reactions can be strong, and they can be unpredictable. With respect to any of these genetic tests for adult onset diseases, whether it is a good test or it is a bad test is a question that can only be answered in the context of the specific test, the specific disease, and the specific individual—his or her life situation, job, family, and personality.

1218.

34. For a discussion of these issues, see Michael J. Malinowski & Robin J.R. Blatt, *Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards*, 71 TUL. L. REV. 1211, 1248-51 (1997).

35. Nancy Wexler was instrumental in the discovery of the Huntington's Disease allele. *See id.* at 1249 n.119.

36. *Id.* at 1248-49, n.119.

C. *Behavioral Genetics*

For some reason, the covers of news magazines seem to be particularly susceptible to news stories about behavioral genetics. It is almost as if things like cancer and diabetes are not as exciting as math ability or sexual preference or violence or other behavioral characteristics. It is clear that there are some genetic links to behavior. Our genes are different from those of chimpanzees. Not very different, but different. And we behave differently. People with "Fragile X" Syndrome are mentally retarded because of genetic differences.[37] Mental retardation is behavior.[38] There is a nasty genetic disease called Lesch-Nyhan Syndrome where children end up engaging in very self-destructive behaviors.[39] It is clearly a genetic disease—and a prime example that genes and behavior *can* be related. But these behavioral genetic relationships, at least thus far,[40] are really hard to tease out. When you read things saying a "gay gene" has been found, do not believe it. In general it is wise not to believe any gene discovery until it has been replicated at least four or five times; this is particularly true of behavioral genetics. I believe there ultimately will be some associations between genetic variations and behavior, but those associations are not going to be very powerful. There will not be a "math ability gene," but there might be a genetic variant where twenty percent of the people with the variant have significantly better math ability. But, at the same time, perhaps ten percent will have below-average math ability. The effects of genes on behavior will likely be small.

D. *Eugenics*[41]

Eugenics is a bad word in the West, thanks to the Nazis, who took eugenic principles so far as to wipe out whole groups of people they thought should not be allowed to breed.[42] But eugenics was not another Nazi outrage. By 1932, at least twenty-six states in the United States passed, on eugenic principles, laws providing

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37. *See generally* Carol Isaacs Barash, *Commentary: "Genetic Testing in Children and Adolescents: Parental Authorities, the Rights of Children, and the Duties of Geneticists"*, 3 U. CHI. L. SCH. 545, 548 (1996) (noting that Fragile X Syndrome is an inherited form of mental retardation).

38. *See* Denis W. Keyes et al., *Mitigating Mental Retardation in Capital Cases: Finding the "Invisible" Defendant*, 22 MENTAL & PHYSICAL DISABILITY L. REP. 529, 531 (1998) (discussing the behavioral characteristics which affect individuals with mental retardation).

39. Such behaviors include self mutilation (including chewing off finger-tips), aggressive behavior, and mental retardation. *See* SHELDON, *supra* note 26, at 281; STEDMAN'S MEDICAL DICTIONARY, *supra* note 16, at 1390.

40. This ignores, of course, the associations between the Y chromosome which determines maleness and things like not asking for directions, hogging the TV controller, and playing football.

41. *See Legal, Ethical, and Social Issues*, *supra* note 1, at 483-84.

42. *See id.* at 484.

for compulsory sterilization of people with bad genes.[43] By 1950, as many as sixty-thousand Americans had been sterilized for their genetic diseases, such as feeblemindedness, shiftlessness, and criminal tendencies, so they would not pass them on to their progeny.[44] I believe we have now been immunized against eugenics. The Nazi exaggeration of the United States experience is sufficiently fresh that the West will probably not go down this path again—at least not in my lifetime, and I hope not in the lifetime of anyone here.

But eugenics, of course, can play more subtle roles. If we pay for prenatal genetic tests as part of health insurance and pay for abortions but do not pay for treatment, is that eugenics? If we pay for phenylketonuria (PKU) tests—and in fact require them—but do not pay for the special and expensive medical diet that people with PKU need, the PKU test requirement potentially encourages abortions. Is that eugenics?[45]

More directly, the West is not all of the world. About three years ago, China, the home of one-fifth of our species, passed a maternal and infant health law that required couples getting married to get a certificate from a doctor.[46] And if the doctor finds either person has a serious genetic condition, the couple can only get the certificate if they promise to be sterilized or use long term contraception.[47] I am also told that in China that if you are not married, you do not have children. Further, if the couple gets pregnant and the doctor believes the fetus is at risk for a serious genetic disease, the woman *must* get prenatal testing and—in some very controversially translated Chinese characters—the law says that she "should" follow the doctor's advice.[48] No one is quite clear what that "should" means. But the statue can be read as saying that if your doctor says your fetus has this condition and you should have an abortion, you *must* have the abortion.

E. Free Market Eugenics

Washington, or even Sacramento or Columbia, is not likely any time soon to tell us we can or cannot reproduce. But parents always want the best for their kids, so why not the best genes? Until recently that has been hard to do. Not very many couples are going to get pregnant over and over again and keep aborting fetuses

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43. *See* Charlotte Rutherford, *Reproductive Freedoms and African American Women*, 4 YALE J.L. & FEMINISM 255, 273 (1992); *see also* Buck v. Bell, 274 U.S. 200, 208 (1927) (holding that state sterilization laws are not unconstitutional).

44. *See* Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 BERKELEY WOMEN'S L.J. 122, 123 (1993).

45. This is not a perfect example because PKU tests generally are not prenatally performed, although it is sometimes tested for prenatally in families who already have had an affected child. *See* Burris & Gostin, *supra* note 15, at 140.

46. Daniel S. Gewirtz, *Toward a Quality Population: China's Eugenic Sterilization of the Mentally Retarded*, 15 N.Y.L. SCH. J. INT'L & COMP. L. 139, 147-62 (1994).

47. *Id.* at 148-50.

48. *Id.* at 148.

because they do not have the right genes for height or hair color or what they think might be an athletic ability. But if a couple is undergoing in vitro fertilization, they can have a procedure called pre-implantation genetic diagnosis.

This procedure is performed when the embryo grows to about sixteen cells. Technicians can take one cell out without hurting the embryo and can then test its DNA. Typically, a round of in vitro fertilization produces ten, twelve, or twenty embryos. They are not all implanted at one time because no one wants the risk of a woman trying to carry twelve fetuses to term. Instead, the clinic will implant three or four; in some places as many as five or six. The clinic must pick which embryos to implant. Right now they look at them under a microscope and they pick out the healthiest looking ones. But they could also do pre-implantation genetic diagnosis and say to the parents, "You are at risk for passing on cystic fibrosis. These eight embryos would be carriers but not have the disease, these four embryos would not be carriers, and these four embryos would have cystic fibrosis. Parents, which ones do you want to implant?"

And if they are testing one gene, they could test many more, someday thousands. So, the clinic could say to the parents, "By the way, of the four that won't be carriers for cystic fibrosis, these two are male, these two are female. This one will be particularly tall, this one will be short—or at least has a better chance of being tall or short." Designer babies will be a reality for at least the next generation, if not my generation. What should we do about it? Should we care about it? I am a parent. Part of my job is to shape my child, to make sure that my son and daughter know right from wrong, are loving and good people, study hard, and root for Stanford. That is my responsibility. I do it through enormous post-birth intervention in their environment. Is it different if I try to shape them, in part, before birth by genetic selection? I do not know the answer to that.

V. MANIPULATION[49]

The fourth major area is manipulation. Is there something wrong or odd about taking genes from one species and putting them in another? This has been a major issue recently with respect to food. Many people do not realize that many of the new drugs, and even many old drugs like insulin, are currently being produced by organisms that are part human and part non-human.[50] Genetically, these cells are 99.99% E. coli or yeast or Chinese hamster; and .01% human. You take the human gene, you put it in some other kind of cell, and have the cell churn things out. Is that troublesome? Probably not.

But what if we start making things that are half human and non-human? What if, like the firm Advanced Cell Technologies, we put the nucleus from a human cell

49. *Legal, Ethical, and Social Issues*, *supra* note 1, at 486-87.

50. *See* Aubrey Milunsky, *The "New" Genetics: From Research to Reality*, 27 SUFFOLK U. L. REV. 1307, 1322 (1993).

into a cow's egg cell?[51] Does that trouble us? The more direct area of this kind of manipulation is human gene therapy, which ultimately will stand and fall on its medical merits and which does not raise particularly difficult ethical issues. But some of these broader issues of creation of chimeras are going to be troubling.

VI. OWNERSHIP AND CONTROL[52]

Ownership and control issues span a wide range of controversies. One set concerns "gene patents." There are two kinds of objections to the current patent process for genes. One objection questions what we should and should not allow to be patented, and what rights should follow from patenting. It does not claim that these patents are bad or good in the abstract, but that we must balance the incentive patents give to firms like Celera to accelerate the Human Genome Project versus the cost, the resulting monopoly. There is another, much more fundamentalist kind of objection coming from religious groups, deep environmentalists and a variety of anti-globalization forces. These groups are strongly against "patents on life" as a fundamental issue. The first set of issues are alive in the policy arena; the second in the political. We cannot know yet how these patent questions are going to be resolved, but they are important issues to follow.

Genetic privacy is another hot issue in the ownership and control of genetic information. Many states have passed legislation protecting genetic privacy.[53] In other states, genetic information is protected, just as medical information is protected. This means that in law, genetic information is protected everywhere, and, in fact, it is hardly protected at all. I believe genetic information really is just another form of medical information. It cannot and should not be separated from the medical information category. Rather than trying to protect specifically genetic information, we should improve our protection for all medical information.

One argument for that regulation is that it is impossible to determine what medical information is "genetic," and what is not. My blood type is "A positive." I have just given you genetic information about myself—about two different gene systems, the ABO system and the Rhesus factor system. My physical audience can make a pretty good guess that I am carrying a Y chromosome (my readers will make the same guess from my first name). Genetic information is everywhere. When a doctor takes a family history, she gets probabilistic genetic information. Genetic privacy laws will be extremely difficult to administer. How does the law limit information that can be inferred broadly and found anywhere? We leave biological information about ourselves everywhere. We shed hair, skin cells, and other small,

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51. Tom Farmer, *Mass. Firm to Clone Embryos for Stem Cells*, BOSTON HERALD, June 15, 1999, at O23.

52. *Legal, Ethical, and Social Issues*, *supra* note 1, at 488-95.

53. Mulholland & Jaeger, *supra* note 29, at 317 ("At least thirty-four states have enacted legislation governing the disclosure of genetic information.").

DNA-bearing biological matter, all accessible to someone who really wanted it. How does the law control that?

It might be impossible to regulate effectively the collection of tissues that have DNA, but perhaps we could control the analysis of the information. A lab, for example, might only be allowed to test a sample if it had signed permission from the person who left it. But even that has problems—for example, what happens if someone gives a blood sample, with full permission, to a doctor for a simple medical test? Could that doctor then test the sample for any disease, or is the doctor limited to the test the patient consented to? While these issues may seem clear, in practice they are not—it is going to be increasingly difficult to protect people from unlimited testing of DNA samples.[54]

VII. CHANGED UNDERSTANDINGS

The deepest effects of the revolution in human genetics on our societies may be the ways in which it could change our understandings of ourselves and our place in the living world. Three areas stand out.

First, comparison of the genes and genomes of different species shows, very concretely, that all life on earth is related. DNA sequences from vastly different organisms show strong similarities. About ninety-nine percent of human genes seem to be closely related to genes in mice; over a third of human genes are found in single-celled yeast. Darwin's claim that all life is related by descent from a common ancestor can be seen in these similarities in DNA. It is unclear what cultural significance this will have. It should not, for example, lead to vegetarianism because the evidence shows that carrots and corn, like sheep and cattle, are our relatives. It might, however, promote greater respect for other forms of life, as reflected in stronger environmental sentiment.

Second, the evidence from human genetics shows that all humans are very closely related. We are all cousins. Our DNA differs, on average, at one spot in one thousand. In the regions of the genome that make proteins, the differences are one in ten thousand. Humans from opposite ends of the earth are far more similar to each other genetically than are chimpanzees from the same band. Genetic theories provided support for a "scientific" racism in the first part of the twentieth century. The new genetic evidence should provide conclusive evidence against such racism.

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54. *See* Henry T. Greely, *Breaking the Stalemate: A Prospective Regulatory Framework for Unforeseen Research Uses of Human Tissue Samples and Health Information*, 34 WAKE FOREST L. REV. 737-66 (1999); Henry T. Greely, *The Control of Genetic Research: Involving the Groups Between*, 33 HOUS. L. REV. 1397, 1397-1430 (1997); Henry T. Greely, Editorial, *Genomics Research and Human Subjects*, 282 SCIENCE 625 (Oct. 23, 1998); Henry T. Greely, *Human Genomics Research: New Challenges for Research Ethics*, *in* PERSPECTIVES IN BIOLOGY AND MEDICINE (forthcoming Spring 2001); Henry T. Greely, *Iceland's Plan for Genomics Research: Facts and Implications*, 40 JURIMETRICS J. 153-91 (2000); North American Regional Committee, Human Genome Diversity Project, *Proposed Model Ethical Protocol for Collecting DNA Samples*, 33 HOUS. L. REV. 1431, 1431-73 (1997) (Henry T. Greely, principal author).

Third, genetics may shift the balance in the debate between nature and nurture. DNA may appear to prove that individuals are powerfully shaped by forces beyond their control, but, in reality, science paints a much more complex picture. Genes play a role in the development of many traits or diseases, but environment or luck are also often essential. Most of the time, the correct answer to "nature or nurture?" is "yes." The general population, however, seems to hold a much stronger belief in the power of genes. For that reason, the new genetics could end up promoting a more closed and fatalistic view of human life and abilities than either current society holds or than science would support. That reaction may prove to be the most significant ethical challenge—and, in the long run, the most important harm—of the revolution in human genetics.

VIII. CONCLUSION

Our new knowledge of human genetics will change human societies forever. It will do that partially through providing new and powerful tools. Like all powerful tools, these can be used well or poorly: they will give us a greater ability to cure or prevent human suffering; they also give us a greater ability to inflict such suffering. The revolution in human genetics, however, provides not just knowledge for creating tools, but knowledge—about ourselves and all other life—that, in itself, can have powerful effects. The consequences of the knowledge gained from genetics may be greater than the consequences of the tools it provides.

At this point, so close to the beginning of the revolution, we are really only guessing about the consequences. Some of the effects seem quite clear; undoubtedly, we are completely overlooking others. It will be the task of those living through this revolution, from our generation and from future generations, to work to ensure that we realize as many of the benefits—and as few of the harms—as possible. For that reason, all of us—as professionals in law, medicine, and science and as citizens—need to follow, and to influence, the implications of the human genetics revolution for human society.