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2000 ASHG AWARD FOR EXCELLENCE IN EDUCATION
Resetting our Educational Sights: Unconstructing the Public's Dreams and Nightmares of the Genetic Revolution*

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Thank you, Dorothy; you warm the cockles of my heart. John McEnroe once said,"The older you get, the better you used to be," and I feel a bit that way about this award. When I think of all the things I could have done, but didn't, I wasn't all that good. Nevertheless, I thank the Awards Committee—and the Society—for this honor, which, however undeserved, gives me great pleasure.

My first experience in genetics education was trying to explain to my parents why I wanted to study genetics, rather than medicine. Explaining wasn't as easy then as it would be now, and I did not do a good job; but they supported me anyway, for which I thank them.

I spent a lot of my professional lifetime writing papers for and lecturing to doctors about why genetics is important in medicine. We don't have to do that any more; the extraordinary advances in genetic knowledge have made it obvious. But that doesn't mean we can stop our educational efforts. Our job is bigger than ever. We must help physicians and paramedical workers learn how to communicate with their patients about the enormous amount of new information on genetic testing. We must teach ourselves more efficient ways to organize genetic services—and to gather, store, and convey genetic information—in the light of the increasing demand for genetic counseling.

I want to talk briefly about a third obligation: to speak out against a number of misconceptions that the public have about the new genetics—some of them overly fearful and some overly optimistic. One fear that gets a lot of press time is that our new genetic-testing abilities will lead to genetic discrimination. Some of us lament how genetics is threatening peoples' insurability and employability, without saying what to do about it. In fact, genetic discrimination may not be that much of a problem in clinical genetics (Billings 2000). Let's start saying, "Yes, we must be careful not to let this happen, but people are working things out." (One way to solve the health insurance–discrimination problem, by the way, is national health insurance. Try it, you'll like it!) Some so-called genetic discrimination isn't genetic. I wrote a letter to the editor in response to a story headlined "Genetic Discrimination," about a woman with A1AT deficiency who was fired because her employer didn't want his company's insurance plan to pay for her very expensive medication—which was genetic discrimination, the author said. But the genetic revolution didn't invent A1AT deficiency. That it is genetic was irrelevant; it was treatment discrimination. I know that nobody reads letters to the editor, but at least one writer and one editor may have learned something. So don't hold back on your letter writing.

Some of the fears that people have about the new genetics stem from the idea that genetic interventions for

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preventing disorders or enhancement of normal traits will alter the gene pool in unforeseen and disastrous ways. Here are some of the gene-pool issues that are raising hopes we must try to deflate—and concerns we must strive to defuse:

The new genetics will allow us to cleanse our gene pool by prenatal diagnosis (PND), to eradicate the bad genes. This would clearly be a good thing but will have eugenic implications and increase discrimination against the disabled. The fear that PND will increase discrimination against the disabled is understandable, and we must try hard to counteract such fears—but not by banning PND. Point out that our "preventive" interventions affect only a small number of pregnancies. The Canadian Royal Commission on New Reproductive Technologies found that "genetic" abortions in 1990 constituted less than 1% of all "therapeutic" abortions, and this number is not likely to rise significantly, because of their highly stressful nature. Preimplantation diagnosis (PID) is rare and will never be widely used, as it involves the inefficient, stressful, and sometimes hazardous procedures of in vitro fertilization. PND is too rare to make significant changes in attitudes to the disabled, which are, in fact, improving. Furthermore, most deleterious genes are not exposed to selection, and mutation keeps adding them to the gene pool, so selection against them would be very inefficient. The gene pool is very stable. We will never make it squeaky clean.

We will be able to use "designer genes" for enhancement of normal traits—and pick and choose what kind of babies we will have. This would lead to discrimination, change norms, and even alter human nature. Those who had been enhanced might be issued with enhancement certificates, which would be an advantage in the job and marriage markets. The unenhanced might end up being considered "disabled."

There is little prospect that there will ever be significant amounts of genetic enhancement, since "normal" traits are very complex, and we are not likely to identify—much less manipulate—a significant number of genes for intelligence, beauty, or whatever. Even if we did, using PID to enhance a normal trait would involve selecting embryos with several—say four—"superior" genes. If each of these genes had a 50-50 chance of being present, only 1 in 16 embryos would be suitable. Not feasible! Furthermore, the use of PID is very limited, even for severe disorders. Widespread PID is unimaginable. I am not prepared to worry about how genetic intervention will alter our gene pool and require us, as some suggest, to reconsider the fundamental problem of distributive justice or decide whether it is permissible to change human nature this way.

Gene therapy might be used to "cleanse the gene pool," cure our ills, and enhance our "normal" qualities, with the same bad consequences as widespread PID. The same counterarguments apply. In addition, *there could be unintended mutations, which could be passed on to future generations "forever."* Point out that mutations are happening all the time and that genetic interventions that affect germ cells will not be numerous. It is unlikely that created mutations would slip through the safeguards, but, if they did, they would not be passed on forever. Dominant ones would be removed rapidly by selection, and recessive ones would add insignificantly to the large number already in our gene pool.

On the medical side, there is the idea that the new genetics has transformed the practice of medicine. Well, it certainly has, in terms of the increasing ability to diagnose diseases and even some predispositions. We will have our hands full learning to cope with the increased demands for service. So let's not oversell ourselves. Here are a few expectations we should try to deflate:

We will all be issued microchip genecards, listing hundreds of loci and the ones at which we are mutant, so we will be able to check out prospective mates to see if they carry the same ones, choose which medications to take if we have certain diseases, and see if we are likely to develop a late-onset Mendelian disorder. Brave new world? But for those of us who would not look forward to this, don't worry, it's not likely to happen. The genecard will never be cheap enough—or precise enough—to be used for widespread screening, and there is allelic heterogeneity (Cederbaum 2000). And think of the confusion and (mis)apprehension that would be caused by such screening without genetic-counseling backup.

We will be able to define our genetic personality from a drop of blood. Nonsense. The genetics of personality is very messy, and the prospect of defining "personality genes" is dim, if visible at all.

We will be able to screen healthy populations for hundreds of susceptibility genes that increase risks for various common complex disorders and select against them by PND or gene therapy; we could also identify which environmental factors increase the expression of which genes, so people could choose lifestyles that avoid specific environmental factors that increase the risk for their particular genotype. Very nice, but it's not so simple. For one thing, the proportion of cases of a common disease that can be attributed to susceptibility-conferring genotypes is likely to be small. For a disorder with a frequency of 1%—and susceptibility genes with a relative risk of 5%—the attributable risk would be about 4% under the most likely circumstances (Holtzman and Marteau 2000). Secondly, susceptibility genes for common complex disorders are hard to find, since they have low penetrance and increase risk only moderately. And do we really want to get rid of these genes, even if we

could? What keeps them in the population? They may well be minor side effects of genes that have major beneficial effects. To identify, in addition, which environmental factors interact with which genotypes would be an enormous task. And who wants to spend money screening for genes with low penetrance and small effects? We can't even decide what to do about "major" susceptibility genes such as *CF* or hemochromatosis, for goodness' sake.

I don't wish to detract from the immense value of the work that's going on in human molecular genetics, which will bring us many benefits, but let's not oversell ourselves, as we did with gene therapy. We should all be thinking of ways to clarify the public's view of the new genetics, allaying fears without inflating expectations. With this, I wish you success and bid you farewell.

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