

Genetics: Life, Death, the Universe and Everything...

Why the title? Genetics really does seem to be worming its way into so many areas of life. For example, we used to speak of cancer and of genetics in completely different categories, but now we recognize that we can't understand cancer without understanding genetics: first, by understanding how and why a cell's DNA goes crazy and second, by understanding how cancer risk can be genetically grounded and transmitted through families. Behavioral issues, everything from autism to shyness to drinking too much, we are now beginning to understand as having a genetic component.

I want to begin by considering a topic known in bioethics as

GENETIC EXCEPTIONALISM

This term was coined, I think by Thomas Murray, to describe the belief—and policies stemming from that belief—that genetic *knowledge* is somehow more potent, more dangerous, more significant than other kinds of parallel knowledge. Two examples of genetic exceptionalism: when Congress approved the Human Genome Project, it set aside 5% of the annual budget to investigate the ethical, legal and social issues spawned by genetic research. And, in 2008 Congress passed GINA, the Genetic Information NonDiscrimination Act. GINA makes it illegal for someone to discriminate against you in housing, employment or health care, because of genetic information about you. For example, someone can't refuse to hire you because you carry the mutation for early-onset Alzheimer's Disease, and they don't want to invest in you only to have you go on permanent disability leave when you should be in your prime working years.

Both these Congressional acts shout that there is something really special about genetics. For example, last year President Obama announced the BRAIN initiative: Brain Research through Advancing Innovative Neurotechnologies. But there's no set aside in *this* program for research into the ethical, legal and social issues of neuroscience, even though there is a whole field of neuroethics.

As for GINA, why is it more important to protect people from genetic discrimination than from discrimination on the basis of other medical information, e.g. that they get frequent colds and are often absent from work? Ironically, if the frequent colds can be shown to be due to a genetic factor, abracadabra, it's covered under GINA!

So the fear here seems to be about misuse of genetic *information*. Let's think about that for a minute. Looking around you at your classmates, what can you know about their genetic blueprint, just by looking at them???? [Note

ambiguities: eye color, hair color, gender, race] Now, what other kinds of information could you get from an analysis of their dna, that you can't see on the surface??????

Some of the ways in which genetic information is thought to be special is:

1- **predictive**– some writers have gone so far as to say that genetic information presents us with a *Future Diary*. What kind of predictive info might we get from knowing someone's genetic blueprint???? (Huntingdon Disease) But, of course, very few genes are as open and shut as Huntingdon: one gene = one disease, and if you have the gene you get the disease. [Even with HD, you might get hit by a truck and die before you ever get the symptoms of HD.] With most diseases, genetics can only tell you that you are at higher or lower *risk*. Remember Angelina Jolie deciding to have a double mastectomy? Why did she do that???? But even with BrCa, her chances were perhaps 85% if getting

breast cancer, and having the double mastectomy lowered her risk considerably, but not all the way to 0. So it's very dangerous to assume that because you have a predisposition, that means you are doomed to a certain fate, and it's also dangerous to assume that, because you don't have a genetic predisposition, you are home free.

It's also misleading to think that genetics is some kind of *exceptional* crystal ball. Given that genetics is rarely 100% predictive, lots of other things can predict a baby's future as accurately as genetics. For example, family income is a great predictor of SAT scores. Students from families earning more than \$200,000 a year average a combined score of 1,714, while students from families earning under \$20,000 a year average a combined score of 1,326.

2- genetics is also thought to be special because if you find out something about my genetic make-up, you find out something about my family as well. For example, if I tell you

that I am a carrier for the recessive genetic disease, Tay-Sachs, what do you know about my siblings, assuming I have any? And my kids? And maybe, if you don't quite get what recessive means, you figure that you shouldn't date anyone in my immediate family, because we've got this scary disease going on, so that could lead to the kind of discrimination and stigma that GINA can't protect us from.

It also means that, if I find out that I'm a carrier, I have to wrestle with my moral obligation to inform my family that they are at risk and should get tested as well. Maybe I am estranged from my brother, or maybe I gave a child up for adoption—or maybe I have an adopted child who doesn't know his true parentage. Things can start looking like a daytime soap opera pretty fast.

In fact, a relatively common scenario is genetic testing that reveals *misidentified paternity*. For example, maybe Dad needs a kidney and son John volunteers to be tested, to see if

he's a match. And the news is: you're not a match (or maybe you are) **and** you're not his biological son. Genetic counselors estimate the rate of misidentified paternity in the US is about 10%, due to infidelity, sperm donation, etc.

BUT there are many nongenetic secrets that implicate families as well, incest, sexual abuse, race passing. If my father is in prison, and my mother has TB and my uncle raped my sister, that information may be way more stigmatizing than anything a DNA analysis could show.

On the other hand, just yesterday I read in the NYT about two developmentally disabled brothers in North Carolina who were released after decades on death row, because DNA tests showed them innocent of a rape and murder for which they had been falsely convicted. This is going kind of far afield, but I do think it's very interesting that when people back in the 1980s and 90s were trying to predict the societal results of the "genetic revolution," everything from

"designer babies" to the collapse of the health insurance industry, one thing I don't recall being mentioned was one that is actually the most clear and dramatic: a widespread loss of support for the death penalty, even among people, like the former governor of Illinois, who support the death penalty philosophically, but are now forced to conclude that innocent people do get wrongly convicted.

NOT DISCUSSED BY Dr. Davis

NOT DISCUSSED by Dr. Davis

NOT DISCUSSED by Dr. Davis

So, for many reasons, genetic information is felt to be especially private, especially dangerous, especially exciting—SPECIAL! Not surprisingly, many ethical conflicts then arise over who has access to the information. GINA already is a powerful example of that: a potential employer cannot have access to that information, or at least cannot *act* upon that information.

Some other examples: 1) All babies in America are subjects of newborn testing in their first days of life, that test them primarily for genetic diseases such as PKU, that could harm them if not addressed. The testing is done by a drawing a tiny amount of blood that is then dried in the form of a “blood spot.” But what happens to those blood spots once the child is tested? Are they thrown away? Are they de-identified and used for research? Who needs to consent to

that? Parents? In Texas a few years ago, parents were so enraged when they discovered that their children's blood spots were being used for research without their consent, that they sued the state and thousands of specimens were ordered to be destroyed.

2- The FDA recently stopped the company 23andme from giving genetic results to consumers. The company worked like this: you sent them \$99 and they sent you a kit to spit in and return by mail. Then they analyzed hundreds of genetic traits and gave you health predictions—for example your risk of developing type 2 diabetes, compared to the general population. Has anyone done that??? 23andme is fighting back, so we'll see where that leads. But the primary question seems to be: do I have the right to get what information about myself that I want, without going through a doctor or a genetic counselor, even if I might misinterpret it or act on it in ways that are harmful?

3- Finally, think of this scenario. You know that, if law enforcement officers want to search you or your car or your premises, they need a search warrant, which means they persuaded some judge that they had reasonable cause to suspect you. The 4th Amendment says: *The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no warrants shall issue, but upon probable cause,* But if something is easily seen, out in the open, then it isn't a "search" and no warrant is required. So if I report my green Mini Cooper missing and you are driving down the street with a Mini Cooper with my license plate number, well, the cop is going to stop you and use that as evidence—he doesn't need a warrant because you and the car were in plain sight. Well, you figure, if the cops want a dna sample from you, that's about the clearest example of a search there can be—reaching into your body through a cheek swab or blood sample to get very, very private information. They need a warrant, right? Well, yes and no. Because in 1988 the

US Supreme Court decided that if a person puts stuff outside his house in garbage bags, to be picked up by the garbage truck, and the FBI opens the trash bags in the meantime and finds drug paraphernalia, then that's not a search and no warrant is needed. Something you "discarded" and put outside yourself in a public space is fair game. So, if a police officer wants my DNA, she has two routes which she can go: she can do the work of persuading a judge that she has probable cause for suspicion and get a warrant, or she can just follow me to the café and wait until I discard my coffee cup, or blow my nose, pick up my dna sample and use it as evidence. It was trash, right? I discarded it, no? That's one of the big legal questions out there—are we going to treat discarded dna like trash, or are we going to give it at least as much legal protection as an object I have in my house or in the glove compartment of my car?

Lots to think about!