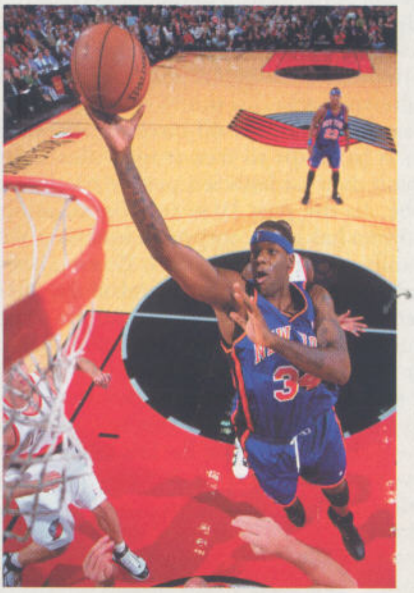
HANDS OFF MY GENES

WHO'S LOOKING AT YOUR DNA?

By Lori Andrews

After Chicago Bulls center Eddy Curry showed signs of an irregular heartbeat last season before a game against the Charlotte Bobcats, the Bulls refused to sign him to a long-term contract. The team instead offered him a one-year contract at $5.1 million, with the requirement that he undergo a genetic test to see if he had a predisposition to heart disease. Curry balked at the testing; cardiologists he'd consulted had declared him fit to play. Even if a test indicated a genetic concern, many men with a genetic marker linked to cardiac disease never develop heart problems.



Before Curry could take the Bulls to arbitration to escape the test, he was traded to the New York Knicks. Although the Knicks won't require the genetic analysis, the issue of testing without consent is far from resolved. David Stern, commissioner of the National Basketball Association, suggested that all potential rookies submit to DNA testing prior to the league draft.

Even if you aren't a professional athlete, your potential employers or insurers—or even the cops—may still want a peek inside your genes. Some seek it for identification—to match DNA to crime-scene evidence or to finger a father through a paternity test. Others, such as employers and insurers, want to save money by turning away healthy people who may later develop costly diseases. According to a 2004 survey by the American Management Association, 63 percent of companies obtain medical information about employees. Some even admit they use the results of genetic tests for sickle-cell anemia or Huntington's disease as a basis for hiring and promotion decisions. But genetic tests are no crystal ball. A woman who is denied health insurance because she has a genetic mutation supposedly linked to breast cancer still has a 50 percent chance of never developing the disease; even more surprising, 90 percent of women who get breast cancer pass the genetic test.

Yet another group—researchers and biotech companies—wants access to people's DNA to search for lucrative genes for research and patenting. In one case, a group of families donated money and body tissue over the course of a decade to identify the fatal gene that had killed their offspring. They were shocked to discover that researchers had patented the gene. The families objected because the patent increased the cost of the test and allowed the patent holder to forbid anyone else from offering that genetic test or undertaking research on the gene. A genetic test without a patent royalty can cost $100 or less. With a patent royalty attached, the cost to the patient can rise to 10 times that. As a result of gene patents, one in four laboratories has stopped performing certain genetic tests. Half have not developed a test for fear they will run afoul of patent law.

The technology is available to use a simple blood sample to sequence a person's complete genome, the 30,000 genes in the body. Affymetrix, a biotech company, already markets the technology. The test itself would be affordable, but imagine the royalty fees if the test for each gene required a $1,000 royalty. Who could afford the $30 million price tag to learn his or her genetic makeup? Even if your doctor were willing to ignore the patents and create a CD-ROM of your personal gene sequence, you'd be violating multiple patents by putting that CD in your computer to check if you had a predisposition to a particular cancer. No wonder the American College of Human Genetics and the College of American Pathologists oppose gene patents.

In our society the law gives extensive protection to our bodies; court cases hold that touching a person without consent is battery and that people have a right to refuse medical intervention and to forbid research on their body. Under constitutional law, people have liberty interests in what is done with their body—including saying yes or no to contraception and abortion—and privacy interests in controlling the dissemination of information about themselves. Yet the law currently fails to protect what is done with DNA.

The need to protect genetic privacy and liberty is great because DNA is so accessible. If you have a blood test or biopsy at a hospital, your DNA may end up in commercial research and product development. New York City's Memorial Sloan-Kettering Cancer Center gave access to cancer biopsies from patients to a biotech company. If you leave dental floss in the garbage, someone could grab the DNA from your gum tissue: Multimillionaire Steven Bing's discarded floss was pilfered for a paternity test. If you agree to give blood for a certain type of research, scientists may use it for unrelated genetic research projects. That's what happened to members of the Havasupai tribe who live in a remote area of the Grand Canyon accessible only by horseback, foot or helicopter. Such isolation is the reason certain genetic diseases occur more often among the Havasupai than in the general population; the tribe has one of the highest incidences of type 2 diabetes anywhere in the world. The Havasupai consented to have diabetes-related research done on their blood samples, but researchers undertook additional unauthorized genetic research on them regarding schizophrenia, inbreeding and population migration. The Havasupai assert that the research on schizophrenia and inbreeding stigmatized them and insist they would not have authorized the migration research because it conflicts with their religious beliefs about their origins.

The legal rights in each of these situations are slim reeds. Only one court—the Ninth Circuit, a federal appellate court in California—has taken genetic rights seriously. In the case, an employer used blood from routine physicals to test African American employees secretly for the sickle-cell-anemia gene mutation. The court ruled in the employees' favor, saying, "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic makeup."

But not all courts are as protective of genetic rights. In 2005 a federal court ruled against the Havasupai's claims that researchers had acted fraudulently and violated the tribe's right of informed consent by conducting additional research.

When other patients whose genes and cell lines had been patented went to court to claim that their "property"—their DNA—had been taken without their consent, the courts ruled that patients could not have a property right in their DNA but that researchers could.

Since courts fall short of protecting genetic rights, advocates of genetic privacy and liberty have turned to the legislatures. As a result, various states have laws that prevent insurers from discriminating against people based on the results of a genetic test. But most states have loopholes that allow insurers to collect genetic information in other ways. Plus, those state laws don't protect the 55 percent to 65 percent of employees who work for companies that self-insure. The federal Health Insurance Portability and Accountability Act provides protections against losing your insurance if you change jobs, but it doesn't protect people in individual plans.

THE GENETIC BILL OF RIGHTS

- You should have the right to refuse genetic testing and not to disclose genetic information, except in criminal cases in which there is individualized suspicion.
- You should not be discriminated against by insurers, employers, schools, courts, mortgage lenders or other institutions based on genetic tests.
- If you undergo genetic testing, you should have the right to control who receives the results.
- Your genes should not be used in research without your consent, even if your tissue sample has been made anonymous.
- Your genes should not be patented.

The federal Americans With Disabilities Act prohibits employers from discriminating against people based on a medical condition unrelated to the person's ability to do the job at issue. But the law allows the potential employer (such as an NBA team) to require genetic testing, and it would be difficult to prove a person didn't get a job because of a glitch in his genes rather than because the winning applicant had more education or a better jump shot.

Only seven states have laws requiring a person to give written informed consent before he or she is genetically tested. In six of these states police can access blood samples without such consent. Five of the seven states allow research on a person's genes without consent as long as the individual's name is taken off the blood sample. Yet people may object to certain research even if their name were to be unattached—such as research in which genes are patented.

In a South Carolina case, an ex-husband in a custody dispute convinced a judge to order genetic testing on his healthy ex-wife to see if she would die at a younger-than-average age. This case may foreshadow genetic battles in all custody cases in which divorcing spouses seek genetic testing on each other in order to predict which one is less likely to get cancer or heart disease.

Do we really want to see a society in which our ability to work, get insurance or even maintain custody of our children is based on a genetic test? In which our genes enter the research and commerce arena without our consent? We should retain our right to reject mandatory genetic tests, genetic discrimination and the patenting of our genes. Whenever a third-party institution—an employer, an insurer or the police—tries to subject you to a DNA test, refuse until you can assess your legal protections. And if you provide blood for medical testing, make sure to find out what will be done with it—and dictate the restrictions you want. Only by being conscientious objectors in the DNA draft can we get policy makers to pay attention.

Andrews, a professor at Chicago-Kent College of Law, chaired the federal ethics advisory committee to the Human Genome Project.