



# GENE BLUES?

**We look beyond the news about genetics research to see how technology can help and hurt us**

By Harriet A. Washington

Keone Penn had reached the end of the treatment road. As a toddler, the Snellville, Georgia, boy had not been just sickened but also devastated by sickle-cell disease. He'd had a stroke when he was 5 that left him temporarily paralyzed and in need of weekly blood transfusions. By the time he was 12, the years of therapy had taken their toll. "In less than a year, he was admitted to the hospital eight times," says his mother, Leslie Penn. "He was extremely weak and always in severe pain that morphine couldn't relieve. He would just scream." Keone was in danger of suffering a second stroke, and his mother knew it could be fatal.

Then, in September 1998, doctors came to her with a faint ray of hope. What if Keone's bone marrow, which harbored the trouble-making genes that were cranking out deformed blood proteins, could be replaced with stem cells from the umbilical cord of a newborn with

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**mind**body



normal genes? Doctors hoped that transplanting the new cells would produce the healthy bone marrow Keone needed.

Leslie knew that this procedure was experimental; it could have killed her son. But his mother also knew how dire his situation was without the treatment. Leslie decided to tell Keone everything and let him decide for himself. He said simply, "I think it's worth the chance. I could die anyway."

After a hellish year of fighting complications, Keone made medical history: He is the first person ever cured of sickle-cell disease using stem cells from the umbilical cord of a newborn. Although Keone's was not genetic therapy in the classic sense, it is a heartening example of how research into genetic disease can improve health care. Genetic therapy has been used to treat people with deadly genetic diseases such as cystic fibrosis, and it shows great promise for other health conditions. But some genetics experts raise concerns about how the technology will be used—and wonder whether Black folks stand to benefit as much as other people.

While genetics should offer hope to African-Americans—who suffer disproportionately from some inherited diseases—we are people whose genes have more often been used against us. The new science evokes images of Big Brother and Tuskegee-type experiments.

## GENE SCREENING

The problem is that for every benefit, there seems to be a potential for misuse. During the 1970's, for example, the federal government supported initiatives that encouraged widespread genetic screening of sickle-cell anemia, which strikes one in every 400 African-American newborns. It also affects people of Mediterranean, Middle Eastern and African extraction. But the National Institutes of Health's policies and publications focused primarily on African-Americans. And many people confused sickle-cell *disease*, which can be deadly, with sickle-cell *trait*, which can be carried by healthy people.

"This created huge problems," says Vernellia Randall, a professor at Dayton School of Law in Ohio. "Airlines, for example, said pilots with the trait couldn't fly. Also for [at-risk] couples who conceived at that time, the advice was pregnancy termination. Some viewed these as attempts to limit the fertility of Blacks."

Another example of questionable use of gene technology was also in the early 1970's. Tens of thousands of Black boys were screened in Maryland and Boston for a genetic abnormality because scientists erroneously thought it caused violent behavior. Similar studies were conducted in the 1990's in New York City—only with African-American and Hispanic boys.

Were these conspiracies? Confusion over the uses

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## HIGH-TECH FINGERPRINTING

The clearest example of how genetic technology can work for our benefit is found in the dramatic stories of how DNA technology has freed more than 70 innocent men from prison. Calvin Johnson was one of them. In 1983, at age 25, he was accused of raping a White woman. Although pubic hairs found at the scene didn't match his, the jury relied on eyewitness testimony to convict him. Johnson ended up in what he calls the hardest work camp in the state of Georgia. He lost his youth, his fiancée and his naiveté, but in 1996 he found deliverance in DNA. He was 41 when he was freed by the Innocence Project, the brainchild of O.J. Simpson Dream Team members Barry Scheck and Peter Neufeld, lawyers at the Benjamin N. Cardozo School of Law at Yeshiva University in New York. They introduced DNA evidence that convinced appeals-court judges that Johnson wasn't guilty of rape.

Developed in 1984, DNA fingerprinting is a method of comparing the DNA of two or more individuals—identifying and comparing genetic markers. Researchers can obtain a DNA sample using blood, semen, hair or tissue from the interior of the cheek. When technicians extract the DNA and "slice" it into short pieces or fragments, they end up with a characteristic striped pattern that looks a lot like a bar code. This is the DNA fingerprint that is uniquely yours—making it useful for establishing disease potential, pater-

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of the new technology? Or both? Even today there is widespread misunderstanding about what genetic therapy is and what it can and cannot do.

## THE ABC'S OF DNA

To understand the latest in genetics news, many of us need a biology refresher. Nearly all your cells contain genes, which, in turn, contain DNA, deoxyribonucleic acid. DNA is a molecule that contains a code that dictates and directs the development of a fertilized egg. DNA is passed from parents to children, and it determines or influences traits from your eye color to a propensity for a disease. Unless you are an identical twin or the product of another such multiple birth, your DNA is unique. No one else on the planet has your exact genetic code—though humans share a great many genetic similarities.

Theoretically, genetic therapy cures disease by changing a person's genetic makeup—replacing faulty genes with healthy ones. On paper it seems like a medical miracle, but so far it has yet to live up to its potential.

Researchers are experimenting with changing the genes in a fertilized egg so that the person will be born with different genes than the ones he or she inherited. The danger of this *germline therapy* is that scientists don't know enough about how genes interact with one another to predict the results. *Somatic gene therapy* is performed after birth (and into adulthood) and involves introducing normal genes to help counteract the effects of an abnormal gene so a disease doesn't develop. Unfortunately, except for a few high-profile cases, the new genes haven't worked.

And then there's the widespread misconception that simply having a disease *gene* means you have the disease. Not so. Most common adult-onset genetically influenced diseases, such as type 2 diabetes, hypertension and cancer, typically result from *several* genetic factors, not a single gene. It often also takes environmental triggers (obesity, nutrient deficiency, exposure to noxious chemicals, for example) to cause the disease to manifest. What's more, genes also interact

with one another to temper the other's effects. All these factors complicate scientists' attempts at gene therapy.

## TWO-EDGED SWORD

It is important to realize that genetic science is a two-edged sword, says Troy Duster, Ph.D., a professor of sociology at New York University. Genetic information can be used to deny health care as well as to cure.

In August 2000 the University of California settled a \$2.2 million suit brought by employees who were surreptitiously tested for genetic disorders, pregnancy and venereal disease. Earlier this year the Equal Em-

nity, guilt or lack thereof. So far, this fingerprinting evidence has helped exonerate 77 men, and the Innocence Project has inspired 15 to 20 similar groups around the country.

So many men have been sprung by such testing that laws ensuring prisoners' rights to DNA appeals have been passed in several states. Yet, ultimately, this technology harbors serious concerns, too.

"The media focuses on African-Americans who have been released from prison by DNA technology," says Troy Duster, Ph.D., a professor of sociology at New York University. "But the same technology that will exculpate people today is also being used to put people stopped by the police into genetic databases."

Soon police will be able to use new technologies to take a quick swab for DNA during a routine traffic stop, run the information through a database via satellite and see if the sample matches genetic evidence in their database—all in about the time it takes to check your license and registration.

If there's no match, you're free to go. But your sample stays in the database—what is essentially a genetic rogues' gallery. Duster points out that innocent African-American men are increasingly being added to these. Recently, Miami police seeking a criminal stopped 2,300 Black and Hispanic men on the street and took DNA samples from each. All these men proved innocent, but police have stored their genetic information in a database to be tapped when police are looking for a "perp." This

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ployment Opportunity Commission charged Burlington Northern Santa Fe Railroad with running genetic tests on workers who filed claims for carpal tunnel syndrome. If the workers had the genetic predisposition for the condition—not one of them did—the railroad argued that it should not be held liable.

And this year a University of Nebraska report questioned whether soldiers with Gulf War Illness were predisposed to it. If sick soldiers are found to have a particular genetic variant, that fact could be used to absolve the military of the obligation to pay them health benefits.

Many people are curious about the health information contained in their genes—it can give them clues to prevention and self-care. But they fear how that information may be used, or how it will affect their privacy.

"Some women seek gene testing [for predisposition to breast cancer] on their own and pay for it out of their own pockets because they don't want their insurance company to know," observes Tene Hamilton, the genetic counselor with the National Center for Bioethics in Research and Healthcare at Tuskegee University. They fear they will be denied health insurance and employment opportunities.

If employers won't hire you because they find out you have a genetic indicator for a disease, some experts say this could create an "unemployable" biological underclass.

And that's not just a concern for folks with known genetic illnesses. Everyone has a few "bad genes"—genes that could, but don't necessarily, indicate a health problem. The more people are forced to reveal their genetic information, the more they are at risk of being discriminated against. Congress released a report that predicts that such discrimination may become widespread as employers are pressured to contain health-care costs.

There are personal as well as social concerns. "If you know of a genetic condition and lie about it to your insurance company, they can refuse to cover you," says Marian G. Secundy, Ph.D., director of Tuskegee's bioethics center. She participates in a National Institutes of Health panel that is considering mandating informed-consent procedures for people who are recruited for clinical trials so they will know that their genetic information might be obtained by an insurance company.

Secundy is also concerned about public-policy efforts advising prenatal testing—perhaps the most common form of genetic screening. Many conditions for which pregnant women are screened have no treatment at all or have treatments that aren't readily accessible.

"If you learn you are at risk for a disease that cannot be treated, the information can be worse than useless," she says. "You will not be able to protect yourself, but you will suffer mental anguish over an illness that you may never acquire."

## FINDING THE BALANCE

The health pros of genetic research might outweigh the cons for some people, but experts question whether it will for Blacks. Such research sometimes bypasses the conditions that affect us disproportionately. Researchers may be able to identify a gene for an illness, but finding a cure for it is another thing

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**'Genetics should offer hope to African-Americans, but our genes have been used against us.'**



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## MINDBODY

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altogether. It may take decades to find a treatment—if researchers are looking for one. And if a disease is common to a smaller group of the population, there's not as much incentive to look.

Too often the interests of African-Americans fall below the radar of genetic research. In the effort to map

all of humanity's genes with an eye to curing many illnesses, 67 families' genes were analyzed, but there were no people of African descent. While some geneticists say there is no genetic basis for race, others believe that severing the African branch of the family tree is a critical error because African gene pools are more richly diverse than others.

## High-tech Fingerprinting CONTINUED FROM PAGE 92

database of Black men constitutes a collective presumption of guilt.

Experts such as Duster and Neufeld say our excitement about freeing these men has caused us to overlook the seriously flawed system that jailed them in the first place.

"The real significance is not that DNA got them out," observes Neufeld, "but that DNA provides a window into the criminal-justice system to see what went wrong with the system to let so many innocent people be convicted."

And DNA evidence isn't foolproof. Some crimes leave no testable materials, and samples often deteriorate, are lost or discarded over the years an innocent person languishes in jail. Relatively few inmates can afford this technology, and courts sometimes ignore compelling DNA evidence. Clearly, DNA technology is no panacea for the justice system that has a disproportionate number of Blacks mired in our nation's prisons. Genetics is no substitute for justice.

—H.A.W.

But given the potential for abuse of the technology, many question whether Blacks should be involved in genetic research at all. If all things were equal, it would probably be to African-Americans' medical advantage to participate. Genetic technologies are the medical wave of the future, and, given our serious health issues, we can't afford to miss out. But we also cannot afford to jump into these murky waters uninformed.

We must protect our genetic privacy as we would anything else that belongs to us. Before agreeing to a genetic test for medical or research reasons, remember that there are ways to protect yourself:

■ If you're approached by law-enforcement personnel seeking to swab the inside of your mouth for DNA to "rule out" you or your child as a suspect, remember that your DNA will become part of a rogues' gallery of crime suspects. Say no and call your lawyer.

■ Never agree

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4 Rinse for a deep clean



3 Wash with textured side



2 Wash with soft side



1 Wet and lather





## MINDBODY

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to gene testing on the spot—even tests conducted by your doctor. Take the time to speak to a genetics expert who is knowledgeable about what can and can't happen to your sample.

■ Trained genetic counselors can help you understand the ins and outs of testing. And they can help you figure out how to proceed once you have your results. Call a local teaching hospital to find a counselor near you.

■ Ask the counselor: What conditions or diseases might this test reveal? What treatments exist for them? How will this test change the treatment I am likely to receive? How will knowing the results affect my care for the better? If you are told that you risk passing a condition on to your future children, ask to have the degree of actual risk, not relative risk, explained to you by an expert. Such risks are often very small.

■ Ask whether treatments exist for any conditions that may be found during

testing. If not, it may be worth it to wait and be tested after a cure or an effective treatment is found. ■

**Harriet A. Washington is a senior research scholar at the National Center for Bioethics in Healthcare Research and the author of *Living Healthy With Hepatitis C* (Dell).**

## INTERIORS

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1993 and halted the execution date that threatened his birthday, we had become close friends.

Though seemingly very different, our lives had points of connection that were meaningful to our growth and political outlook. Both of us had been teenage parents who had veered off the orthodox path early in life. We had wandered until we turned youthful adversities into reasons to become empowered adults. Behind bars, Shaka had overcome a cycle of pain stemming from childhood abuse and neglect that led to adolescent drug addiction and juvenile violence. He had grown into a vibrant and

articulate leader and scholar of the Black experience. In open society, I had become an educated advocate and professional committed to the development and progress of my community and other oppressed peoples. Both late bloomers, we had a message for young brothers and sisters and the 2 million in prison. In our shared philosophy, every human being was full of potential waiting to be realized and transformed into a force that could uplift mind, spirit and soul. We believed there was not a lost soul on this earth. In the beginning I struggled, often faltered, but Shaka gave me a level of confidence and optimism that buoyed me above the churning terror of genocide that is the death penalty.

I learned to stare at jailers and executioners at the eleventh hour and continue to believe I would be the victor. Shaka taught me that. I saw him do it every day. I stored his lessons of strength and vigilance and hope inside me, so I could take them to others to sprinkle like juju dust in every school and prison and ghetto and place that a soul or body is under subjugation.

# Have more than one good side

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1 Wet and lather



2 Wash with foaming soft side



3 Wash with textured side



4 Rinse for a deep clean



2SIDES  
2CLEAN





◀ In "Juvenile Injustice" (page 147), veteran reporter **Katti Gray** examines the case of Miriam White, a 14-year-old charged with murder, to reflect on the question of whether the court system should try children as adults. "Miriam's case is absolutely heartbreaking—for her, for her victim, for us as a people—for all it so tragically symbolizes," Gray says.

▶ "From childhood, shy people are made to feel as if we have a character flaw. One of my goals in writing this was to debunk that myth," says **Ziba Kashef**, *essence.com* senior editor. She discusses the roots of shyness and how to conquer it in "Shy? Here's How to Shine" (page 142).



◀ On page 153, **Eisa Nefertari Ulen** (right) pays tribute to her friend, photographer Mfon Essien (left), who died of breast cancer earlier this year. "Mfon came to this earth to create beauty, share truth and touch souls," Ulen says. Before Mfon passed on, she left this powerful message to Black women about breast cancer: "What is paramount is early detection. Go get yourself checked."



◀ "I took my first genetics course 15 years ago, and it has been an interest of mine ever since," says **Harriet A. Washington**. She dispels misinformation about DNA testing and gene altering in "Gene Blues?" (MindBody, page 88). ■



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# contributors