

Is Genetics The New Astrology?

By **Simson L. Garfinkel**
Staff writer of the Christian Science Monitor

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AS genetic testing becomes more widespread, a growing number of people may find themselves denied insurance, employment, and social services, solely because test results indicate a genetic predisposition to a certain disease.

The first signs of an emerging genetic underclass have already appeared, according to a recently completed survey by Paul R. Billings, director of the Clinic for Inherited Diseases at the Harvard Medical School's Deaconess Hospital.

Using responses to a magazine advertisement and a leaflet sent to 1,119 genetics professionals across the United States and Canada, Dr. Billings documented nearly 30 instances in which people were discriminated against solely because they had been diagnosed as having a genetic disorder. Most of the respondents were able to supply supporting evidence of their claims.

"The people had very, very minor manifestations of genetic diseases," says Billings. "Many of these people are not sick in an objectionable way, but they are treated as if they . . . have a significant disability." Among the disturbing cases Billings found:

- A salesman who had driven his car for 20 years without incident had his auto insurance canceled when his insurance company discovered he had been diagnosed with a mild form of Charcot-Marie-Tooth (CMT) disease, a neuromuscular disorder that can cause weakness in the extremities.

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Even though the man's doctor wrote a letter to the insurance company saying the disease had no impact on the man's driving, the company refused to reinstate the policy.

- A woman mentioned that she had a mild case of CMT during her pre-employment screening at a telephone company. The examiner asked her what CMT stood for, looked up the disease in a medical book, and denied her the job, even though it had already been promised to her by a company recruiter.

- Two women who each had a parent with Huntington's disease - and thus were considered to have a chance of developing the disease themselves - decided to adopt children. Both were disqualified. "We feel that a 50-50 chance of getting a disease as serious as Huntington Disease is too great a risk," wrote one of the adoption agencies.

- A pregnant woman whose fetus tested positive for cystic fibrosis, a children's disease associated with pancreas and lung problems, was told by her health-maintenance organization that if she didn't have an abortion, the organization would limit its coverage of the pregnancy and the resulting child.

Because of the way the survey was conducted, it isn't possible to know how widespread this new kind of discrimination is.

"I got the impression that they probably were isolated cases," says Dr. Robert Pokorski, medical director of Lincoln National Life Insurance, who is critical of Billings's work.

But Gary Marx, a professor of sociology at the Massachusetts Institute of Technology, says the prevalence of the discrimination doesn't matter: "The issue with new technology is not 'Is it widely abused?' The questions that have to be asked are 'What is the danger? Where will this lead?'" Genetic discrimination could lead to a society in which people are stigmatized not by diseases they have, but by diseases they might get.

Already, says Billings, a negative medical record can prevent a person from working for an employer who is unable or unwilling to afford higher medical insurance premiums. The genetically marked who do have insurance might become "afraid to change jobs, and speak up at work," for fear of being unable to secure new insurance with a new employer, he says.

Such gene-typing overlooks the fact that many people who have the genetic potential never develop the corresponding illness or the problem is so slight that the disease goes undiagnosed and unnoticed.

People once believed that their lives were determined by the positions of the stars at the moment of birth. Are some people now ascribing that power to the arrangement of a person's genes? Genetics could become the astrology of the 21st century.

personal gain. "What right do we have that no one else in the world should ever have the good deal we had?" Gunther says.

Proponents counter that cashing out in 20 years was part of the original deal. Actually, few gave the matter much thought when Mitchell-Lama was enacted, legislative sources say.

The buy-out contest at Penn South was a war of leaflets and official debates. Residents say this is typical. With its 10 stolid-brick structures, Penn South looks like many city housing projects. But its political culture is unique. "I love meetings at Penn South," says Marian Rothman, head of the Council of New York Cooperatives. "When they call a meeting, you can count on 600 people coming out."

Penn South was financed by the garment workers union under a renewal program similar to Mitchell-Lama, and many residents once walked to work in the city's garment district. President John F. Kennedy came to dedicate the project in 1962, and long-time residents still speak of the event as an "anointing." "There's an honor to this co-op and we always felt we had to live up to it," says Ruth Vogel, a retiree who lives there.

This spirit has helped turn a development of more than 6,000 people into a real community.

The co-op needed to draw on every bit of this community spirit to fight the buy-out. It was a rare opportunity to get rich overnight. Residents, most of them retired, were hearing prices like \$200,000 for apartments they paid \$8,000 for in 1962. "It was an invasion of the barricades and the sharks," says David Smith, a Penn South resident and board president since 1972.

The debate was intense and sometimes bitter. But in the end, Penn South residents surprised just about everybody by deciding to remain in the co-op program.

Penn South seems reasonably safe for another 25 years. But other co-ops don't have its political cohesion. A bill to rescue them by extending Mitchell-Lama has been languishing in the state legislature. Complicating things further, the financially strapped city stands to gain millions in new property taxes if the co-ops go private.

Yet some residents are worried about the future of Penn South. Newcomers who didn't experience the labor wars and JFK's speech just don't have the same co-op spirit. "It's lost on the younger generation," says Arthur Vogel, a playwright and Ruth's husband.

Unlikely Oil Magnate

By **Keith Henderson**

HE was a militant, a patriot, an African nationalist, and an American capitalist all wrapped in one. Jake Simmons Jr. was his own kind of original, a man whose life begs the descriptions, "self-made man," "beating the odds," and "rugged individual."

But as Jonathan Greenberg explains, oilman Simmons had an advantage over fellow African-Americans of his generation. His family roots were in the Creek Indian nation of Oklahoma. Early in the 19th century, blacks fleeing slavery were welcomed into the tribe. Jake Jr.'s great grandfather became a chief. The rights to land and self-government accorded the tribe's members applied to black Creeks too.

A code of self-reliance took hold among these people. Simmons's father and mother, Jake Sr. and Rose, built a productive cattle and farming business. They demanded good working habits and a commitment to learning from their 14 children.

After a youth spent learning the cowhand's trade, Simmons headed to Booker T. Washington's Tuskegee Institute. He had already decided his father's life in ranching was not for him. Dr. Washington's philosophy of self-sufficiency through marketable skills appealed to the young Oklahoman. And the Tuskegee principal's way with words fascinated him. Simmons's love for self-betterment lectures would never wane - to the occasional dismay of his children.

Son Donald Simmons recalls a father who demanded excellence. "If you made an A, you had to make an A plus, or ask if they gave A pluses. You didn't get any compliments from my father for being ordinary, or as good as."

The 160-acre allotments given members of the Creek nation by the US government were Simmons's entree into the petroleum business. He began by brokering his own allotment to interested drillers, then provided the same service to neighbors with promising holdings.

Business soon expanded to the oil fields of east Texas. Simmons had his share of "dry holes," wells that sputtered instead of gushed, but his optimism never dried up.

Greenberg does a thorough job of filling in the hostile social environment Simmons operated within. The year after Jake Jr. started his oil brokering, Tulsa erupted in a race riot. In the '20s, Oklahoma had more than 100,000 active Ku Klux Klan members. "Grandfather clauses" and "at large" districts kept the state's large black minority away

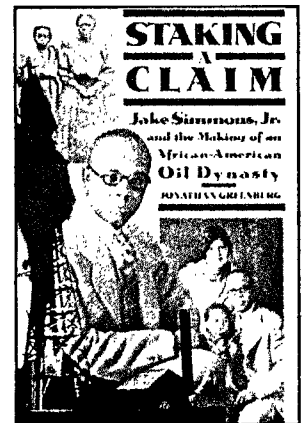
from polling booths and public office.

Greenberg in fact peppers his narrative with references to the racial attitudes Simmons confronted. Like most of the book, these anecdotes are related in a readable, journalistic style. Occasionally the pace slows. Overall, though, the text moves well.

Jake Simmons responded to racial affronts with the same directness he used to lecture a child or barge into a corporate office, deal in hand. He wouldn't take the insult, "boy," from anyone and kept himself and his family armed and ready - a fact known to local racists.

Simmons's pride in his African

BOOKS



STAKING A CLAIM: JAKE SIMMONS, JR., AND THE MAKING OF AN AFRICAN-AMERICAN OIL DYNASTY
by Jonathan Greenberg
New York: Atheneum
295 pp., \$19.95

heritage led to the biggest business deals of his life. While serving on a federal commission examining economic development in Africa, he made contacts with African ministers of state in charge of mineral resources. Using those contacts, Simmons became a trusted middle man between American corporations looking for new sources of oil and the continent's post-colonial governments. Simmons shared the Africans' desire to move their newly independent countries toward economic autonomy. He also shared the capitalist's instinct for a profit.

This was a man who believed in the American system. He could make the crucial distinction, it seemed, between sound principles and flawed practice. Simmons's story, stitched together here through extensive, well-documented research, is one that Americans of all races will find instructive.

■ Keith Henderson is editor of the Monitor's editorial page.