

Genetic Testing May Mark Some People As Undesirable to Employers, Insurers

By DAVID STRIPP

Staff Reporter of THE WALL STREET JOURNAL

To all outward appearances, Joshua is a healthy, normal two-year-old. But his medical record may permanently brand him as undesirable to insurers and employers.

Joshua has been diagnosed as suffering from an inherited disorder called polycystic kidney disease. But he's not really suffering. The disease, which damages the kidneys, usually doesn't cause health problems before adulthood and may progress slowly even then.

Yet when Joshua's father recently changed jobs, the new employer's health insurer wouldn't cover the child because of his predisposition to the disease. "We finally got health insurance for Josh" with a different insurer, says his mother. "but we didn't tell the company about his disease."

Joshua's case illustrates an issue usually raised on y by experts gazing darkly into crystal balls and foreseeing the classification of people by their genes. A number of similar cases have surfaced, suggesting that the issue already is hitting home. Besides grappling with insurance problems, people known to have disease-associated genes reportedly have been denied jobs and the chance to adopt children.

Such anecdotal reports — circulated among genetics experts recently — aren't "hard evidence" that genetic discrimination is occurring, cautions Philip Reilly, head of Boston's Shriver Center for Mental Retardation. "But concern is appropriate. . . . The reports may be very early warning signs" of discrimination, which "could be a big problem 10 years from now, when we might have 100 tests for genetic diseases." Such tests could put millions of people into high-risk disease categories, branding them for insurance and employment purposes in much the same way those diagnosed with AIDS infections are often marked.

Health and life insurance companies typically require access to the medical records of people seeking coverage and ask about pre-existing medical conditions; people who don't disclose such conditions risk losing their insurance.

deleted recommendation art of an EPA report that ed the scientific literature -level radiation's health ef- That report, minus the rec- gation, is to undergo scien- peer review, the spokes- 1 says, adding that the re- s could decide that there's i evidence to warrant rein- ; the analysts' warning.

Fill in New York ps Its Higher Prices

EW YORK CITY wants its garbage back.

In December 1988 the people more than doubled the its huge Fresh Kills landfill ten Island. Haulers balked, ing 25% to 30% of the land- itake—a monstrous 10,000 f trash a day—to less expen- undfills in Ohio, Pennsylva- id other states.

a diversion inflamed a bor- ar originally touched off by fersey's policy to ship vast its of its garbage to other

Last month, Indiana Sen. Coats tried to attach an iment to a chemical- ns bill that would have let ban or otherwise impede ow of out-of-state garbage. is killed by a cloture vote.)

th New York buried under a crisis, a spokesman for the sanitation department says partment has proposed roll- ick the Fresh Kills dumping o \$25 a cubic yard from \$40 urbage from which recycla- have been removed. Though ; still higher than the \$18.50 rs were paying before the ncrease, sanitation officials they can woo back 3,500 enough coffee grinds and an bones to raise an extra- filton a year in revenue.

Prevalence of Some Genetic Diseases

Estimates of the number of Americans having diseases with a genetic cause or an important genetic ingredient:

DISEASE	INCIDENCE	NATURE OF ILLNESS
Adult polycystic kidney disease	300,000 to 400,000	Kidney damage and failure
Down's syndrome	250,000	Range of mental retardation
Sickle-cell anemia	50,000	Impaired circulation; anemia, pain
Cystic fibrosis	30,000	Chronic respiratory infections and digestive problems
Huntington's disease	25,000	Progressive mental and neurological degeneration
Duchenne muscular dystrophy	20,000 to 30,000	Muscular degeneration, weakness
Hemophilia	20,000	Uncontrolled bleeding
Phenylketonuria	Below 10,000	Mental deficiency
Alzheimer's disease	2 to 4 million*	Progressive mental degeneration

*Hereditarily may account for only a fraction of these cases.

Sources: Office of Technology Assessment and various disease foundations

away. Meanwhile, insurers and employers—squeezed by soaring health-care costs—are trying harder to minimize financial risks posed by chronic, costly diseases. Improved tests for genetic diseases give them new, powerful tools for limiting their exposure to those risks.

"If an individual had undergone genetic tests and had information about them, an insurer would want to know" when making coverage decisions about the person, says Jude Payne, a senior policy analyst for the Health Insurance Association of America, a trade group. "While some people might consider that discrimination, the insurance industry would consider it standard policy."

But testing for a genetic disease typically gives a prediction of illness that says little about the course of the disease and the costs it might entail. The age of onset and the severity of gene-associated diseases vary widely due to patients' differing life styles, treatments and little-understood effects of the "expression" of genes. It's "cockeyed" to base insurance or employment decisions on such hazy predictions.

ing to do, according to a survey of geneticists and other medical professionals that Mr. Billings recently conducted with three other researchers. Among 29 cases of "genetic discrimination" reported to them were ones in which:

—A patient diagnosed as carrying a gene for Gaucher's disease was denied a government job because of the diagnosis despite the fact that the patient wasn't expected to get sick. The disease, which causes liver enlargement and other problems, occurs only in people whose cells each have two copies of its "recessive" gene—one from each parent.

—A pregnant woman whose fetus was diagnosed with cystic fibrosis was told by her health maintenance organization that it wouldn't cover the child's medical expenses. The HMO later reversed the decision after the woman complained.

—A couple's application to adopt a child was denied because one spouse had a family history of Huntington's disease and was at risk for the inherited disorder, a fatal disease that causes progressive mental degeneration.

With Marlboro decals on boro billboards in video fac Marlboro logos scrawled a T-shirts, Marlboro maker certainly looks like it v smoke.

Philip Morris has denied ages children to smoke, mammoth cigarette company will try to prove that: It plans to announce a crack-down on the unauthorized use of its cigarette logos by children's toy and game companies.

In recent months, Philip Morris and other cigarette makers have been criticized for standing by idly while close likenesses of their video games, toy cars, and Morris doesn't give permission brand names to be used for other products. It hasn't actively cracked transgressors, either.

The crackdown, and the Morris hopes to stir with it today, isn't about to appease the company's critics, who are already the move as posturing.

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says the aide.

Ends

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about pre-existing medical conditions; peo-
ple who don't disclose such conditions risk
losing their insurance.

Research advances of the past decade
already have vastly amplified doctors'
ability to diagnose and sometimes palliate
disorders caused by faulty genes. But
cures generally remain years or decades

EDUCATION

Freshmen Flood Black Colleges, Defying Trend

By SUZANNE ALEXANDER

Staff Reporter of THE WALL STREET JOURNAL
While many universities expect fresh-
man class sizes to drop this year, a num-
ber of historically black schools are report-
ing a boom in freshman enrollment not
seen since the 1970s.

Improved recruitment and higher visi-

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Hemophilia	Below 10,000
Phenylketonuria	2 to 4 million*
Alzheimer's disease	2 to 4 million*

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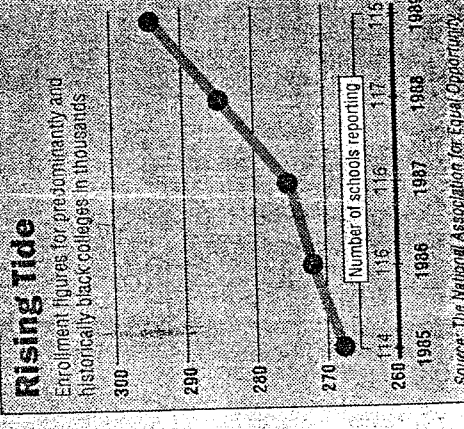
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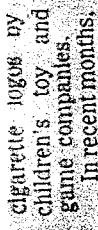
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Argues Paul Billings, who directs genetics
at Pacific Presbyterian Medical Center in
San Francisco.

That, however, is just what a number of
insurers and other organizations are start-



Source: The National Association for Equal Opportunity



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The critics take Philip Morris to
too, for accusing other companies of k
ing its cigarette brands to kids—
Philip Morris itself, intentionally o
does precisely that.

"It's a little bit absurd, when thi
Please Turn to Page B5, Column 3

TECHNOLOGY

U.S. Agency Stands in Way Of Computer-Security Tech

By G. PASCAL ZACHARY

Staff Reporter of THE WALL STREET JOURNAL
REDWOOD CITY, Calif.—A tiny soft-
ware company has developed what is prob-
ably the best defense yet against computer
snoops, hackers and viruses, but the Na-
tional Security Agency is blocking efforts
to expand the technology's use.

RSA Data Security Inc.'s approach is
already widely used in Europe. In the U.S.,
a number of companies, including Novell
Inc., Lotus Development Corp. and Digital
Equipment Corp., have licensed the tech-
nology to protect their messages, and recipi-

ricelli, chairman of a House subcom-
that will hold a hearing tomorrow o
puter security. "We are accom-
nothing but losing a foreign mark-
RSA Data's products are gen-
praised by security experts because
are an advance over traditional "one-
encryption. Each user has a secret
code, and a public key published
rectory and both keys are produc-
linked—by a mathematical "fun-
Senders use the addressee's public
route their messages, and recipi-

CHNOLOGY & HEALTH

Unveil New Line Vaxes to Counter IBM

In a further reflection of the changing market, Digital has redesigned its newest VAX for client-server computing, in which one or more computers act as servers or hubs for networks of smaller desktop machines. In a departure from traditional design, the new VAX has several processors nearly as powerful as the central processor that are dedicated to speeding up data traffic on the network and allowing especially fast access to disk-storage devices.

The new line, to be called the VAX 4000, delivers more power than IBM's top-of-the-line AS/400 minicomputer, at less than half the cost, Digital Vice President Bill Demmer said Friday.

"The real competition is IBM, and always has been," Mr. Demmer said. He said several smaller competitors such as Compaq Computer Corp. and Sun Microsystems Inc. present "short-term tactical situations" but that IBM remains Digital's key strategic focus.

Dean Witter's Mr. Stevens called the new line aggressively priced and said it appears somewhat faster than expected. The models will range in price from \$60,910 to \$329,000, depending on configuration.

The VAX 4000 makes its debut at a scaled-back DECWorld sales exposition in Boston, the first in two years. At the show, Digital also is expected to introduce new network-management software, computer servers dedicated to tasks such as database access or intensive scientific computing, and products that tie computer networks together and connect them to high-speed optical data links.

Found to Account Injuries Among Youth

"The efforts, the money and the research have gone into diseases, but injuries haven't received that kind of attention," Dr. Rodriguez said. "With the same type of effort, we could decrease the impact of injuries on children."

Almost half of the injury-related fatalities in 1986 stemmed from auto accidents. Of those 10,500 deaths, between 15% and 19%, according to the CDC, were linked to alcohol use.

Homicide, the second-largest category among fatal injuries, accounted for nearly 3% of the childhood deaths. While the majority of these fatalities occurred among youths age 15 to 19, almost one-quarter—60 homicides—involved children under the age of five.

The third-leading cause of fatal injuries was suicide, accounting for 2,151 deaths in 1986. Among children age 10 to 19, males accounted for 80% of the suicides. Of those, an estimated 60% involved firearms.

Genetic Tests Brand Some as Undesirable To Bosses, Insurers

Continued From Page B1

dotal reports say nothing about its prevalence. "I really disagree . . . that there is rampant discrimination," says Robert Pokorski, chairman of the American Council of Life Insurance's genetic testing committee. "Insurance companies can't make money by denying risk."

Moreover, in a preliminary study at Johns Hopkins University, researchers found that people with neurofibromatosis, a genetic disease that can cause disfigurement, "lacked insurance at about the same rate as the general population," says Reed Pyeritz, who led the study.

Still, many medical experts worry that rapidly proliferating genetic tests are cracking open a Pandora's box. More than 4,000 genetic disorders have been identified, and tests for dozens of them are now possible. (For economic and other reasons, many potential tests aren't yet practical for wide use.)

The dizzying pace of genetic findings is expected to accelerate further as the \$3 billion federal Human Genome Project, which is aimed at identifying all 100,000 or so human genes, takes off in the coming year. Among other things, the 15-year project promises to elucidate genes that contribute to major scourges such as heart disease, cancer and Alzheimer's disease. "The insurance issues raised by genetic screening are about to grow phenomenally," says Harry Ostrer, a geneticist at the University of Florida.

Currently, all 50 states require screening of newborns for certain diseases, including genetic ones. And optional prenatal testing for genetic disorders is surging.

Last year Kim Roembach-Ratliff of Prairie Village, Kan., had prenatal tests that showed her son would be born with spina bifida, a crippling disorder associated with faulty genes in which part of the spinal column is exposed. About the same time, her husband applied for health coverage under his new employer's insurer.

"When we called the agent [for the new insurer]," she says, "he told me, 'I'm sorry, we can't extend insurance to you' " because of her child's expected health problems. Those problems have turned out to be relatively minor, she adds, and her six-month-old son probably will be able to walk with leg braces. Meanwhile, the couple has been able to get an 18-month extension of coverage under the previous employer's health insurance program.

In Columbia, Mo., Mark Gibson, a manager with American Fidelity Assurance who handled the couple's application, says it was denied because the spina bifida diagnosis represented a "pre-existing" medical condition not coverable under the company's rules.

Desmarais, Frere Cement Partners Will Combine Holdings in Pargesa

By G. PIERRE GOAD

Staff Reporter of THE WALL STREET JOURNAL

MONTREAL—Canadian financier Paul Desmarais and Belgium's Albert Frere cemented their new alliance but stayed mum on their ultimate plans for the two European holding companies they control, Pargesa Holding S.A. and Groupe Bruxelles Lambert S.A.

Messrs. Desmarais and Frere said they agreed in principle to formally combine their holdings in Pargesa and GBL. Their combined 50% interest in Pargesa, a Swiss investment concern, will be transferred to a new holding company equally owned by the Frere group and by a subsidiary of Power Corp. of Canada, which is controlled by Mr. Desmarais.

Mr. Frere's 8% interest in GBL will be transferred to a second new holding company, also equally owned by Mr. Frere's group and the Power Corp. subsidiary. Pargesa holds an additional 37% of GBL, giving Messrs. Frere and Desmarais effective control of GBL. Mr. Frere is also chairman of GBL. A Power Corp. official said the 37% block of GBL will continue to be held by Pargesa.

Messrs. Desmarais and Frere announced in February that they held 50% of Pargesa and intended to work together closely. Since then they have been working out the details of their alliance, but haven't said much about their investment plans or

how the partnership will

A Power Corp. official said "our intention is jointly to combine the holdings of Pargesa and GBL, but declined to elaborate. He said the plan in principle will be signed this summer.

Pargesa and GBL have been in the same house since Messrs. Frere and Desmarais teamed up. In a series of complex transactions the two companies sold certain interests in each other and reorganized their holdings. In French banking circles, Pargesa and GBL are known as the "Power of Paribas." Through Mr. Frere and Mr. Desmarais, each owns 10% of Paribas, giving them a strong voice at the merchant bank.

As Pargesa and GBL have been accumulating cash, giving them a sizeable war chest, Pargesa and GBL both companies are active in making investments.

Bolstering their case, Desmarais's substantial holdings in Power Corp. investment funds funneled through Pargesa and its Power Financial Corp. each sold major interests in the companies last year. At March 31, they had about 750 million (US\$645 million) in cash and investments.

Emile Quevrin, a GBL director, said recently that part of GBL's asset sales will be to reduce the company's interest in big Brussels-based oil companies, to 25% from a 40% stake. Quevrin said "we aren't in a hurry" that GBL will wait for the right conditions.

Regarding other possible moves, Mr. Quevrin would only say that GBL is in industries with which it has a long experience. At a shareholders' meeting in May, Mr. Frere said he would seek high-quality companies that have a significant influence on the economy.

That may reflect Desmarais's influence. As chairman of Power Corp. in North America, Mr. Desmarais usually seeks a company that invests in

Northern Telecom

Northern Telecom Ltd. is making an effort to streamline operations by closing a small manufacturing plant in John, New Brunswick.

The facility, which has been operating since 1970, manufactures inductors and other electronic equipment. The shutdown will reduce the number of facilities. Northern has closed similar

Honda's Acura Again Tops An Auto Satisfaction Index

By a WALL STREET JOURNAL Staff Reporter

AGOURA HILLS, Calif. — For the fourth year in a row, Acura, the luxury car division of Honda Motor Co. of Japan, topped the customer satisfaction index of J.D. Power & Associates, an auto market research concern.

Mercedes-Benz AG of West Germany, a unit of Daimler-Benz AG, Toyota Motor Corp. of Japan, Detroit-based General Motors Corp.'s Cadillac and Honda had the other top-ranked nameplates in the index, which is used by car companies in marketing campaigns.

The index is based on a survey of owners of new autos about their level of satisfaction with their vehicles and dealers after a full year of ownership; this standard ruled out consideration of two new luxury cars, Toyota's Lexus and Japan-based Nissan Motor Co.'s Infiniti.

GM's Buick was the only other domestic nameplate in the top nine besides Cadillac, though Dearborn, Mich.-based Ford Motor Co.'s Mercury and Lincoln made big jumps from a year ago. Five of the top nine spots were grabbed by Japanese companies; two spots were taken by German luxury nameplates.

The customer satisfaction index is different from the initial quality survey, released last week by J.D. Power. The

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...third-leading cause of fatal injuries, homicide, accounting for 2,151 deaths in 1986 among children age 10 to 19, males accounted for 80% of the suicides. Of those, an estimated 60% involved firearms. Burns, scalding, burns and other miscellaneous injuries accounted for almost 7,000 deaths.

...out 20% of all hospitalizations among children stem from injuries, including 16 million emergency-room visits. More than 30,000 children each year are permanently disabled because of their injuries.

...that toll, the report suggests, could be reduced by, among other actions, increased use of child safety seats in autos, reduced access to firearms, and improved identification and treatment of individuals at high risk for suicide.

Computer-Security Solution Is Blocked by Federal Snoopers

Continued From Page B1
...s Mr. Bidzos's story. "The project was on the back burner" because it was clear who was really responsible for the eloping standards—the NSA or us," the official says.

The NSA has long influenced the civil use of electronic security measures, mostly by intense political lobbying and mostly through federal limits on the export of cryptographic products. In 1987, a report by the Office of Technology Assessment criticized the NSA's sway over civilian use of cryptography, saying the agency's actions had been "inconsistent," and raised questions about "the boundary between civilian and military authorities."

Seeking to shift some control of computer security, including cryptography, back to civilians, Congress several years ago approved a law giving the Commerce Department's Institute of Standards and Technology the power to set commercial, non-military standards in the area. Last year, Rep. Torricelli's subcommittee told the institute to develop a standard for public-key cryptography but allowed the NSA to help.

More than a year later, the two agencies still haven't produced a draft standard. The NSA spokeswoman says the agency is "cooperating" with the institute, but Rep. Torricelli thinks the two are deadlocked. "There are conflicting interests between a perceived need to allow intelligence agencies to operate freely and [providing] sufficient protection for our private businesses," he says.

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Most tests for genetic diseases are now done prenatally or at birth. But there may soon be more testing of adults, partly because of a trend toward self-insurance among employers. (Self-insured companies directly fund their employee's health plans.) Such employers "have a strong incentive to find out about employees' health risks," including genetic diseases, says Deborah Stone, a Brandeis University professor of law and social policy.

Few, if any, employers are believed to be testing workers for genetic diseases. But a federal study indicated that more than half of employers medically screen job applicants, and many companies request access to medical records that may contain the results of genetic tests.

Fearful of being denied insurance or other things, some people who suspect they carry disease-associated genes—perhaps because of family histories of a disease—decline to use new tests that could put black marks on their medical records. "We get about a call a day from people asking about getting tested for Huntington's disease," says Richard Myers, who directs a testing program for the disease at Boston's Massachusetts General Hospital. "But we only do about three or four tests a year." One reason is that a Huntington's test can cost \$3,000 to \$4,000. But "the greatest deterrent to getting tested," he adds, "is that it makes people feel more vulnerable to losing whatever protection they now have" via jobs or insurance.

Currently, "the legal protections against genetic discrimination are quite fuzzy," says Brandeis's Ms. Stone. It's unclear, for example, whether laws barring discrimination by employers and insurers against people with disabilities apply to people with genetic diseases.

Laws to protect people with medical problems don't always work, anyway. "AIDS testing by employers is illegal everywhere, but it's still done by some companies," says Mark Rothstein, a University of Houston authority on medical screening.

Some states have set up "high-risk" pools for insuring people who can't get commercial health insurance, typically funded in part by insurers. But the pools probably would be overwhelmed by the number of risky cases potentially identifiable through genetic testing. "Ultimately," says the Shriver Center's Dr. Reilly, "the best solution to the problem may be some sort of national health insurance."

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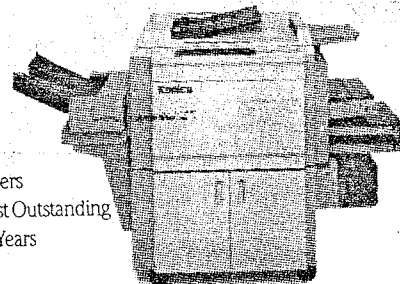
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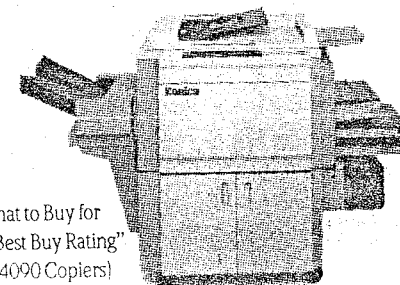
"The business for those plants [in St. John] has gone away as technology has changed," a spokesman said. "Production will be absorbed elsewhere where we have overcapacity."

Six Ways To Make A Worker

1
Recognized by Buyers Laboratory as: "Most Outstanding Copier Line" Two Years in a Row



2
Recognized by What to Buy for Business with a: "Best Buy Rating" (Konica 1790 and 4090 Copiers)



3
Recognized by Hanson's Guidelines as having: "Highest Possible Rating in Performance/Value" (Konica 3290 Copier)

