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Would you gaze into a genetic crystal ball?



A cheek swab by longevity specialist Elaine Chin could pinpoint the illness that will one day end a patient's life. But, as Carolyn Abraham reveals, the emerging form of DNA testing raises a host of troubling questions

By CAROLYN ABRAHAM

Medical Reporter

Saturday, December 31, 2005

When Garry Zentil was well on his way to dropping 13 kilograms (30 pounds) this summer and feeling better than he had in years, he was offered a chance to peek into his medical future.

"Sure, why not?" the 49-year-old executive thought.

At 6 foot 4 and with hands the size of oven mitts, Mr. Zentil doesn't scare easily. So with a swab of his inner cheek, a nurse collected cells for an emerging brand of crystal-ball medicine -- a DNA test that promised to reveal his potential health risks and the illnesses that could one day befall the fit father of three.

All Mr. Zentil knew about genetics was what he had gleaned from movies or the television drama *CSI: Crime Scene Investigation*. But since a previous detection of his high insulin levels led him to a low-carbohydrate diet that helped him lose weight, he had cultivated a certain faith in medical testing.

"It crossed my mind that I might find something I didn't want to know," he said one recent morning in his North York office. "I figured I'd deal with it."

Genome tests will be popular, official predicts

Scientists have long envisioned a future in which the power of genetics becomes a tool for prediction. Just as cloud formations can offer a hint of the storm to come, gene mutations can indicate a person's susceptibility or resistance to a range of conditions. Now, to the surprise of even some experts in the field, that future is here.

A private Toronto-area health-care clinic is offering a DNA test that screens the genes of healthy patients to assess their risk of developing everything from cancer to cardiovascular disease, osteoporosis to obesity.

Scientia Health of Mississauga, Ont., has sold and administered the \$2,000 test to several dozen Canadians, including Mr. Zentil. Their DNA samples are then sent for analysis to the Austrian company that developed the test. The clinic uses the results to help design a preventive health and lifestyle plan aimed at reducing those risks.

"Most of my clients are aged 45 to 50 and they know they are likely going to die of heart disease or cancer," said Scientia's founder Elaine Chin, "They want to know, 'Can you give me a hint as to which way it's going?'"

While it appears to be one of the first such tests on the Canadian market, several other firms in the United States and Europe are gearing up to read your genome. Among them are companies developing over-the-counter kits that allow people to swab themselves, mail off their cells and receive a forecast of their DNA's potential dangers by post.

Yet the more widely available these tests become, the more social, ethical and legal questions pile up: Just how sound is such genetic information, especially if it is subject to no external accreditation or quality control? What can or should an individual, or the public health system, do about conditions that may never materialize? And just who should have access to that information? Employers? Insurance companies?

"It's going to be something society will spend a lot of time discussing," predicts Bruce Waygood, co-ordinator of health research at the University of Saskatchewan. "The reality is that this is a service that is going to be in demand. We pay people to go and read our palms. We have a penchant for wanting to know what's in store for us. The genie is out of the bottle."

* * *

On a four-lane suburban strip near the Trillium Health Centre, where neon lights flash promises of fast health care -- Walk-In Ultra-Sounds! X-rays! -- Scientia Health hovers above it all in an office building set slightly back from the Queensway.

From the moment you walk in the door, it's all about service. An assistant shakes your hand, hangs up your coat, shows you to a sitting room of elegant Asian furniture and offers herbal tea. Newspaper articles decorate the walls describing Dr. Chin's sophisticated private-sector health-care approach that tries to slow or reverse the aging process with particular lifestyle tweaks and treatments.

Dr. Chin, 41, a polished sliver in a fitted suit and blunt cut, is a family doctor, an MBA graduate and self-described longevity specialist. "Prevention is key," she said, clicking through her lap-top power-point slides. "We all say it, but we need to start practising it."

Scienta offers a battery of blood tests, scans and psychological exams. It customizes diet, fitness and vitamin supplement plans and provides access to a naturopath, trainer and nutritionist.

Dr. Chin knows her market.

"They are boomers between the ages of 45 to 55, generally healthy, hold key jobs . . . run companies," she said. "They're executives, entrepreneurs, men and women. Those over the age of 60 tend to come as a couple."

Dr. Chin used to own the health-spa-like Beresford Clinics in Toronto, but in 2004 she reinvented her business as Scienta to emphasize medicine over esthetics.

That same year, at the World Congress of Anti-Aging Medicine in Chicago, where firms touted a sweatless aerobic machine and a hyperbaric chamber to boost blood flow by simulating the sensation of dropping 2,100 metres (7,000 feet), Dr. Chin discovered Genosense Diagnostics.

That company was launched in 2001 as a spin-off of research at the Medical University of Vienna. Evidence had emerged that women taking hormone replacement therapy could face a higher risk of breast cancer and heart disease, and Genosense began by analyzing gene types to pinpoint which women might still be candidates for the once popular menopausal treatment.

"Some genes predispose women to a higher breast cancer risk if they receive HRT; other women not," Genosense CEO Christian Schneeberger said in a telephone interview from Vienna. "There are women as well who have gene types, that if they get HRT their risk of thrombosis increases dramatically. . . so this was the starting point."



Photo: Deborah Baic/The Globe and Mail
Elaine Chin, medical director and co-founder of Scienta Health, poses for a portrait with a model of a Helix.

GLOBEANDMAIL

BY CAROLYN ABRAHAM

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"We analyze only those genetic variations that can be counterbalanced by a specific kind of preventive medicine, by changing your diet, by changing your lifestyle . . . or many other things," said Dr. Schneeberger, who is also a biochemist.

To find those genetic traits, a team of 12 researchers combs medical literature searching for studies on the significance of certain gene variations. Most are variations known as single nucleotide polymorphisms, or SNPs for short, that change the chemical code of a gene and can predispose or help to protect a person from a particular condition.

A SNP in a gene that metabolizes fat, for example, might increase the risk of blood clots and strokes. Another gene variant might increase the chances of developing tumours. Some SNP mutations might determine how quickly or slowly your body processes a drug.

Genosense then convenes a second group of specialists to determine which gene variants have enough research behind them to be included in its DNA test and adds new ones every two to three months.

"We analyze only those for which there is excellent evidence in the literature," Dr. Schneeberger said.



Prof. Christian Schneeberger, PhD



The company is currently testing 73 genetic variants and business is booming. Five hundred doctors around the world are selling its genetic test. Under Austrian law, the company can only provide the test to physicians. Through them, the company has screened 6,000 people.

After Dr. Chin met Genosense representatives in Chicago, she flew to their Vienna headquarters on the university campus to meet their specialists "to assure myself that they were a highly professional group of scientists with a leading-edge lab."

"Their ideas to use genetic testing to prevent illness and disability fascinated me," she said. "It complemented my type of practice."

Dr. Chin is not a geneticist. But Genosense doctors promised they would interpret the meaning of the gene tests, and by combining it with her patients' medical profiles, they could also recommend how to apply the results to their health care.

She recognized immediately the appeal this would have to a savvy, aging generation that prides itself on being health conscious and pro-active.

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Long before he walked through Scienta's doors last winter, Mr. Zentil had worked hard at staying healthy, making a religion of his exercise regimen. He plays tennis three times a week, sees a personal trainer twice and squeezes in a weekly squash match.

Mr. Zentil has no intention of growing old before his time.

His 76-year-old father, who founded the family's thriving property development and management business in 1954, inspires him. Joe Zentil Sr. still runs on the treadmill and plays tennis six days a week. When people ask him about estate planning, Garry Zentil likes to joke that he's leaving everything to his dad.

Mr. Zentil turned to Scienta on the recommendation of a friend after realizing that, despite his regular workouts, he had been slowly gaining weight over the past two decades.

Dr. Chin discovered his high insulin count and taught him to "retrain my pancreas" by rethinking a rice and pasta-heavy Italian diet. So after he started losing inches like a boa sheds skin, he was instantly curious about the genetics test: "I wondered what else she might be able to find out."

There were things about his medical inheritance he already knew. His grandmother had a "weak heart" and he has an arrhythmia, for which he takes daily medication, including Aspirin. He also knows he may face a higher risk of colon cancer since his mother was diagnosed with the disease six years ago. Doctors recommended he undergo regular colon cancer screening and they discovered polyps, which they removed, on his first test.

Still, Mr. Zentil understands not everybody would be comfortable getting a glimpse of their genes. His wife has been mulling over the test for months.

Dr. Chin said more than 50 per cent of her clients choose to have the test. For competitive reasons, she would not divulge the exact number. Ten per cent of clients, she estimates, choose not to have it because they fear the results. Others "don't want to pay for it."

Scienta's "bells-and-whistles" program that includes the genetic test costs \$6,000.

Dr. Chin has taken the test herself. As she suspected, the results indicated that she faces a higher risk of cancers. This came as no surprise. Relatives on her mother's side of the family have been riddled with cancer, of the uterus, the breast, the colon.

What difference did the result make to her life?

Too Soon for Genetic Predictions, doctors says

"I don't put anything but glass in the microwave," she said, saying she fears that other materials may give off carcinogens. She limits barbequed fare and eats nothing charred, for the same reasons.

Other patients have also benefited from the knowledge, she said. One client, a smoker, learned he faces a higher risk of lung cancer and it cemented his will to quit. Another woman, who "works out like crazy," but has had little success reducing her body weight, took comfort in the revelation that she carries a gene that predisposes her to obesity.

Dr. Chin said the results have also enabled her to practise more precise medicine. One test result prompted her to switch a patient's hypertension medication and the client's blood pressure "came down like that," she said, snapping her fingers.

She suspects her patients may be more likely than the general population to undergo this type of testing because they are "already self-selected" as a group that has come to her to find out all that they can to prevent illness.

To her point, Mr. Zentil puts it this way: "The more information you have, the more power it gives you to deal with your everyday life.

"I want to know even if there is nothing I can do, because maybe you do things differently," he said. "What do you do if you find out you have a week to live? I don't know, maybe you say yes to that trip to Vegas."

* * *

But just how much does modern science know about the human genome?

Not enough, according to Roderick McInnes, scientific director of the Institute of Genetics, which is part of the Canadian Institutes of Health Research, the country's main funding agency for health research.

Dr. McInnes is among those who believe it is too soon to shift predictive genetic science from the lab to real life. "We'd all love to be there, but we're just not there yet," he said.

In the case of rare diseases such as cystic fibrosis or Huntington's disease, which are caused by a single gene mutation, the predictive value is crystal clear, said Dr. McInnes, co-author of the definitive reference text *Genetics in Medicine*.

But for common conditions such as cancers or heart disease, which involve multiple-risk factors, he said, the current understanding of genetics presents a fuzzy picture of the future at best. "Genes make a very complex contribution to the development of disease that may, in the end, only develop as a result of certain lifestyle factors, or, if you contract a particular infection, many other factors. The point is, we just don't know what those factors are."

A 2003 article in the journal, *Nature Genetics*, noted that hundreds of gene-disease associations have been made, but said many "prove on follow-up to be spurious or much weaker than originally predicted."

Researchers at The Centre for the Advancement of Genomics in Maryland, an independent policy research body, wrote that a gene variant associated with one condition might, for example, be mitigated by a variation in some other gene. The article concluded that preventive genetic testing is simply "not ready for prime time."

Dr. McInnes, who is also senior scientist at The Hospital for Sick Children and professor of pediatrics and molecular genetics at the University of Toronto, said a mutation in a gene known as APOE that has been linked to Alzheimer's demonstrates the point.

While 40 per cent of people with the disease have this particular APOE gene type, 60 per cent do not. "Most of the population carry one or two copies of these [APOE] alleles [gene types], but it does not mean that they will ever get the disease."

Even if a person finds out he is a carrier, he said, "What do you about it? Play cards, and use your brain more?" referring to research suggesting exercising the mind like a muscle can help keep it sharp.

Dr. Schneeberger acknowledges science is still in the early stages of understanding genetics, but he disputes the idea that offering a test for preventive purposes is premature. It may "take 20 or 30 years" to understand the function of all genetic mutations, he said. "But should we stop and wait until we have [the millions of mutations] assigned? We should use the knowledge that we have."

Research on some gene variants dates to the 1980s, he said, and some of it provides valuable information. A woman found to be genetically predisposed to blood clots, for example, should not be on the birth control pill, he said.

Speaking generally about explaining genetic test results to patients, Dr. McInnes said experience has convinced him that, "No matter how you phrase it, to many people it sounds like destiny, like genetic determinism, like fatalism."

Some people, he said, might resign themselves to the idea that they are going to develop a condition like high blood pressure, for example, and do nothing to try to prevent it.

Tim Caulfield, director of the Health Law Institute at the University of Alberta, said predictive genetic tests, which he thought were still "five years away," could create "the worried well." The tests stand to gain popularity with the baby-boom consumer intent on fighting aging, Prof. Caulfield said. "You have to ask, will they be the worried well, worried over conditions that will never materialize? Then they go to the doctor and say, 'Treat me.' Will the public system have to bear the costs?"

This form of testing also raises serious issues around privacy and genetic discrimination, Prof. Caulfield said.

Employers may seek to use genetic testing to identify someone who could turn out to be less productive or a strain on the company health plan. Insurance companies may refuse clients found to be at high risk of certain conditions.

Hypothetical fears have already played out in the United States. The Burlington North Santa Fe railroad company paid \$2.2-million to settle a suit after it tried to test employees for their genetic predisposition to carpa tunnel syndrome. A Florida woman sued the employer who fired her after a genetic test showed she carried a rare gene variant that can result in a liver disease. Last spring, the Chicago Bulls wanted to run a DNA test on basketball player Eddy Curry after finding he had an enlarged heart. Mr. Curry, who refused the test some experts said would be inconclusive, has since been traded to the New York Knicks.

In the United States, insurance companies have agreed to a five-year moratorium on the use of genetic tests. Washington passed a genetic anti-discrimination bill in February, and most states now have legislation on point. But no such law exists in Canada, Prof. Caulfield said.

Dr. Waygood, at the University of Saskatchewan, noted the field also cries out for regulation to protect the consumer against companies offering unreliable information. In 2001, Dr. Waygood was among those who sounded the alarm about a Saskatoon company, Genometrics Corp., which promised fee-for-service genetic testing. The founder of the company, which never did test any patients, was not the expert he claimed to be and has pleaded guilty to several fraud-related charges, including bilking investors.

Still, Dr. Waygood sees the value in genetic testing for preventive purposes. "If it allows you to make lifestyle changes and undergo surveillance, it might be cheaper than having someone occupy an ICU bed for many months later.

"One could be accused of being paternalistic if the view is not to allow access to such information," he said. "In the end, if people want this information they should be able to get it."

* * *

A few weeks after his swab, Mr. Zentil received his results from Vienna.

Dr. Chin sat with him for an hour explaining the findings. "I understand these are just associations," he said, "I know there are no guarantees."

The testing revealed Mr. Zentil has a higher than average risk of developing prostate cancer and osteoporosis and a borderline chance of becoming hypertensive.

The higher prostate cancer risk has, as with his known family history of colon cancer, convinced him of the need for regular screening. He has also undergone a bone scan so that he will have a baseline for comparison should his skeleton begin to deteriorate and osteoporosis actually sets in.

But Mr. Zentil also feels he walked away with some good news. He tested negative for one of the gene variants associated with Alzheimer's disease.

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Mr. Zentil understands that genetic information represents a double-edged sword. As an employee, he said he would want the findings to remain private and be judged alone on his ability to perform a job. But as an employer, he admitted, "I'd want to know if someone is going to be a burden on the company health plan."

On his office computer, Mr. Zentil has kept a gag e-mail that recently made the rounds. It's an audio file of a man ordering a pizza in 2010 from a company that has access to all his personal information. It charges him \$60 extra for requesting double cheese, telling him it's a risky choice given his high cholesterol levels.

"Now that's scary," he said.

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