

## WHOSE GENOME IS IT ANYWAY?

BY KATHY MALHERBE

THE JOB IS HIS. THE WELL-OILED COGS OF HIS FIVE-YEAR PLAN ARE TURNING. A BARRAGE OF PSYCHOMETRIC TESTS REVEALS AN OPEN-MINDED, GIFTED, PERSUASIVE, INGENIOUS, ADAPTABLE, PRUDENT RISK TAKER.

He has a charismatic 'can do' attitude. He is fit and disciplined. His body is his temple and the habit Armani. A tough negotiator, he has proposed an impressive financial package. The cost to company is staggering. All that remains between him and the role of merger and acquisitions director is the result of a DNA sample swabbed from inside his cheek.

All it takes is a gob of spit and some hard currency to find your identity, otherwise referred to as your genetic coding

THE RESULTS ARE ... **DISAPPOINTING.**

GENETIC FINGERPRINTING |

**T**his 'potential master of the corporate universe' has a genome glitch. The DNA fingerprint reveals alarming

psychopathic tendencies (a 52 percent propensity). He is a potential Snake in a Suit. And not a terribly healthy one at that. He has a 32 percent chance of developing deep vein thrombosis and suffering a stroke by age 50.

Science fiction? It was real enough for the then president, George Bush, to introduce the Genetic Information Nondiscrimination Act – (GINA) – in May 2008. GINA protects US citizens against discrimination in employment and health insurance. And not without reason. Millions of fragments of DNA can be stored on a silicon microchip, and each DNA chip is loaded with vast amounts of highly sensitive personal information. The computer – and as a result, the Internet – can take this personal information into the public domain. The individual's most private details are out there for all to peruse.



It all started with the Human Genome Project – a kind of intensive analysis of your genes and the large bits of DNA between them. It took 10 years of collaboration between the world's top geneticists to sequence the entire genome and track down what was responsible for inherited disease. Over 4 000 disorders caused by defects in genes were identified.

It explains the number of people who are Googling 'Deoxyribonucleic (DNA) + fingerprinting' and choosing one of the many companies offering genetic testing. Personal DNA profiles are the rage. All it takes is a gob of spit and coughing up in the currency of your choice for the privilege of finding your identity.

Welcome on stage 'Retail Genomics'. Companies which will, for the price of a smart new cellphone – between R2 500 and R6 000 a spit – do the analysis. Such is the accolade from those who matter, that a company rather cleverly called 23andme (we have 46 chromosomes – 23 pairs) was voted the *Times* 2008 Invention of the Year. But not everyone gives the techno trend a thumbs up.

Professor Raj Ramesar, head of Human Genetics at the University of Cape Town, is unimpressed. 'It is this kind of thing that has the potential to give genetics a bad name. As much as there is a great deal of positivism about understanding bite-sized pieces of one's genetic material – very little is known even to "genetic experts". Yes, the 46 chromosomes contain the DNA which is your unique genetic code, but the commercialisation – without adequate public understanding – is somewhat distressing.'

DNA is really complicated and so is the interpretation of your unique personal genome. The spiralling double helix of information contains two metres of previously confidential information, twisted back on itself around a core of proteins. Rather like

PRIVACY IS THE BUZZ WORD IN GENETIC SCIENCE AND THERE ARE SERIOUS ISSUES ABOUT SECRECY, ANONYMITY AND CONFIDENTIALITY WITH GOOD REASON

a double-jointed escape artist folded into a circus trunk.

But geneticists have found the key and the secrets of the human genome have leapt out, surprising some and delighting others. And causing a great deal of consternation. Privacy is the buzz word in genetic science and there are serious issues about secrecy, anonymity and confidentiality with good reason.

Our outwardly appropriate candidate for the position of Director: Mergers and Acquisitions finds himself judged by his genes. As his prospective employers weigh the high cost of employing him against the long-term prognosis revealed by the genome test, he discovers that, in fact, the director position is not secured. His DNA profile weighs heavily against him.

Hard on him, but it does make sense that employers would welcome a quick peek at your genome.

After all, it's DNA that decides if you are to be a diva or a dullard, a rocket scientist or

a drop out, a bunny hugger or a hunter. Or a psychopath with a dicky heart.

According to a recent article in *Time* magazine, genetic fingerprinting can provide really vital information. And some extraordinarily detailed but arbitrary information such as 'has the ability to taste bitterness in broccoli and cabbage' and 'face doesn't flush when tipsy.' Nice to know, but it's the sterner stuff – like 58.4 percent chance of becoming obese by the age of 59, a 34 percent chance of having a coronary before age 60 or early onset of Parkinsons – that's the kicker. It's all potentially discriminatory information in the wrong hands.

Stigmatisation, by way of your genes, is not new. Critics of transparency around genetic make-up refer to historical abuses: involuntary sterilisation of people with mental retardation around the turn of the century, and Nazi abuse and misrepresentation in pursuit of eugenic goals.

So, will a genetic profile really determine your propensity for getting a physical or psychiatric disease, or an unsociable predisposition? Enough to lose a job?

'To a degree,' says Professor Ramesar. He explains how a defective gene on its own may not be a problem. But combined with a conducive environment, it could be one.

'Think of it as holding your left and right hands in front of you. One is the defective gene and the other your environment. Alone they don't amount to much. It is only when your hands clap together that a significant noise is made. So, some disorders – an over-refined diet, a rough childhood or obesity – on the one hand, may meet with a genetic weakness on the other. The clap will then result in colon cancer, psychopathic tendencies or type 2 diabetes, respectively.'

Since 1952, when Watson and Crick announced that they had 'cracked the secret of life,' the world has been fascinated by the extraordinary discovery that DNA is just as revealing as the mini barcodes used in store scanners. Just like the barcode – where there is a great deal of shared information in the code – 98.6 to 99.8 percent of the genetic material



A DNA sample is taken from the cheek of Indian cricketer, Sachin Tendulkar. It will be featured in a book on the cricketer, published by Kraken Opus

in humans is identical, which means you might be rather similar to those you could consider culturally or economically further down the food chain. And size doesn't matter. You may only have a few hundred more genes than the lowly mouse or a hovering fruit fly, and it's worth a humble moment considering that we humans have fewer chromosomes than a fern ... It's the subtle and ingenious ways they are arranged which determines the chemistry and characteristics that make each person so unique.

This scientific equivalent of 'finding yourself' has titillated the well heeled who have wasted no time in jumping on the genewagon. While smart investors seek fortune, others seek flaws. Google has invested millions in 23andme, and society 'icons' like Ivana Trump, Rupert Murdoch and Warren Buffet have bought into looking for their little Achilles heels – or trying to prove their absence.

'23andme is faddish,' says Professor Ramesar, wasting no time with niceties, 'and a conversation piece at dinner tables. But I'm not surprised people are investing in genetic fingerprints. The market is huge. Who doesn't want to know what the future holds? The problem is the risks aren't well understood and there are population bases

which can be almost meaningless at the individual level.'

Despite assurances by these companies that 'people can take these results to their physician and integrate them into a healthcare programme', Professor Ramesar adds, 'I would imagine that taking risk estimates to your physician firstly needs the physician to understand the implications of population risk on an individual, and for him to buy into this kind of crystal-ball medicine.'



It seems that gazing into the future is not restricted to medical issues. DNA is the new matchmaker.

Eric Holzle, founder of the DNA dating company Scientific Match, explains that his company compares six genetic markers in human DNA to define compatibility between potential mates. It is based on a theory that people are attracted to others with different immune systems than their own, so they can create healthier children, which is nature's survival of the fittest aspiration. These perfectly matched couples supposedly have a healthier sex life.

Professor Ramesar says wryly, 'There is no single gene or six-pack that makes

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individuals attracted to each other beyond a hormonal rush.' And he finds the idea highly, well, undesirable. 'Science makes it possible to investigate pretty much any aspect of the human condition – correlation with looks, physique, sportiness, disease susceptibility, and so on. My sense is that it is a bit of a money-making racket,' he concludes. And, of course, there is a sucker born every day.

Dating aside, what of the future of genetics? Procreation of the fittest only? And being judged on all levels by your genome? Perhaps the futuristic movie, *Gattaca* – a nightmarish look at human genotyping – is not absurd. Where your CV is a genetic profile, your job interview a urine test. Vincent, the myopic and vertically challenged hero, succeeds despite his genetic 'challenges' by buying a genome superior to his own from a cash-strapped genius.

Is this the future as the Genome Revolution gathers momentum? Getting into your dream job by buying a black market genome so that your flaws remain a secret? Perhaps, but for the moment, The Genome Privacy Act will deny employers the right to the indiscriminate swabbing of prospective employees.

Playing God about your DNA fingerprint to decide if you are in fact a wunderkind or a liability waiting to happen is illegal. You will continue to wear your potential on your sleeve and not in your genome. For now, your genome is your own. ♦

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