Damned by your DNA – an ethical travesty

KATHY MALHERBE

CASTER SEMENYA has had notoriety thrust upon her in such a pejorative way that her exquisite victory in the women's 800m World Championships is paling in significance.

The public has been outraged and titillated by the "Semenya revelations".

An apoplectic Sport and Recreation Minister, Makhenkesi Stofile, has threatened World War 3.

As the media dissect, speculate and feast on this perfect front-page story, and Athletics South Africa (ASA) boss Leonard Chuene is exposed as a liar, hearts go out to Semenya who has received as much unwelcome attention as a circus freak.

Semenya, just 18, has been let down by ASA, athletics and doctors, and described by *3rd Degree* as being "sacrificed at the glittering altar of gold". It must be a bitter disappointment for her.

International Olympic Committee (IOC) president Jacques Rogge has warned of severe emotional trauma – citing the suicide of a star female track athlete after testing male.

Apart from the humiliation and the insensitive debate about her most intimate biology, Semenya's raison d'être – athletics – is being threatened.

At the centre of it all is a flagrant violation of basic principles in clinical medical practice. It is unethical to sneak a look at someone's medical records, much less trumpet them to the public through the media.

The revelation of Semenya's DNA was made with unprecedented crassness. And it violated our constitution and the Declaration of the Rights of Patients set out in the World Medical Association's guidelines including the right to information, confidentiality and dignity.

Associate Professor of genetics of UCT and a DA MP, Wilmot James is adamant that turning someone's biology into public property goes against patients' rights. He says: "(This is) an opportunity for South Africa to ensure robust protection in terms of privacy of genetic information."

The excuse that issues around genetic privacy are all new is perhaps the reason why it was left out of the recently gazetted Protection of Personal Information Bill (August 14, 2009) – a situation which prompted James to write to Justice Minister Jeff Radebe and suggest that it would be a "propitious moment to add the relevant clauses and bring our legislative efforts up to date with modern times". Protocol around genetic privacy is not enough. There was no response.

Interest in digging dirt up on people's DNA is relatively new.

Ever since James Watson and Francis Crick identified DNA and RNA (for which they were awarded the 1954 Nobel Prize), scientists have been fascinated by the most extraordinary molecules on earth. Now, the public has caught on.

And since the Human Genome Project, people have been scrambling to find out what exactly is locked in their DNA and that of others. The 10 years of collaboration between the world's top geneticists to sequence the entire genome produced what James describes as "assemblies of chemical letters that send signals to proteins to make the biological apparatuses of all living things".

Although this genetic fingerprinting has huge advantages for medical science, there are challenges as so soundly demonstrated by the Semenya saga. Issues of balancing confidentiality and autonomy against privacy, integrity, and self-determination reveal that the solutions are not clear-cut.

There is also a real possibility of genetic discrimination by unscrupulous insurance companies, medical aids, employers and now athletic bodies, too. And not without reason. The human genome carries all the genetic information required from conception to adulthood.

What is potentially threatening is that millions of fragments of DNA can be stored on a silicon microchip loaded with unimaginable amounts of highly sensitive personal information. And the computer and internet can take this personal information into the public domain.

Globally, privacy concerns around the collection, storage and sharing of genetic information are being debated. It was enough of a concern for President George Bush to introduce the Genetic Information Nondiscrimination Act or Gina law in May 2008.

Gina protects Americans against discrimination in employment and health insurance. The UK, too, has laws in place to protect DNA information. Supporters of these laws point to historical abuses like involuntary sterilisation of people with mental retardation around the turn of the century, and Nazi abuse in pursuit of eugenic goals.

Knowledge of one's genetic makeup and predisposition may stigmatise the person, just as in Semenya's case. With this in mind, Stofile said his department was "consulting" with its lawyers regarding the human rights violations against Semenya.

James points out that if the protocol governing privacy between patient and doctor is not adhered to, "doctors will be charged with professional misconduct – a serious allegation which can result in their being struck off the roll".

There are also international guidelines on the collection of genetic material.

For example, the doctor taking the sample must mark it and "decouple" or "delink" the patient's name from the sample using a code so that no one in the testing lab can connect the sample with a name.

Only once the results are returned to the doctor are they linked or coupled again.

There is also strict protocol around respect for persons and families, unbiased presentation of information and informed consent.

Professor Raj Ramesar, head of human genetics at UCT, says: "The chain of confidentiality in Semenya's case and custody with regards to handling the material has definitely been severely compromised."

But he points out that taking responsibility is a nightmare. "Guilt and conviction," he says, "are two separated issues".

Caster Semenya did not sign a release form allowing the world to know her most intimate genetic make up. The international media pressure was high – high enough to perhaps encourage the information to "slip out".

Ramesar predicted, quite correctly, that people would "scream their heads off about this travesty of justice" but still believes there will be "little or no recourse for Semenya or those representing her".

"What it will hopefully do," he says, "is to create a climate where athletes are informed of their rights and assured protection."

These were not dope tests; they need consent forms of a different nature.

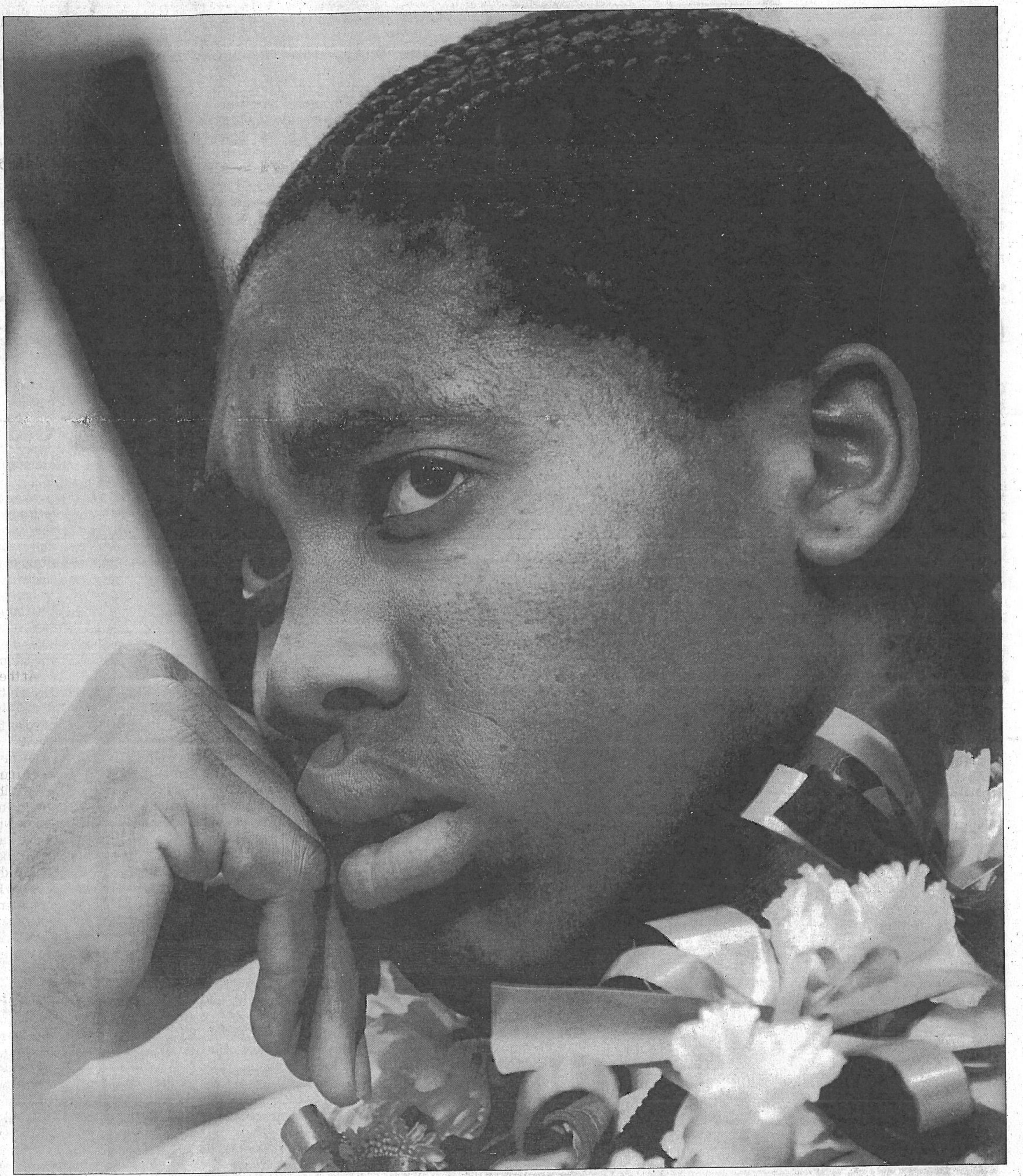
The IOC saw fit to drop mandatory gender exams just before the 2000 Sydney Games because it said "the screening process – chromosome testing – was deemed unscientific and unethical".

This decision was made despite the fact that genetic testing over five Olympics had revealed gender anomalies in 27 of 11 373 athletes.

Eighteen-year-old Semenya is a gifted athlete damned by her DNA.

"Let's hope public understanding and the establishment of law in South Africa around genetic privacy are the winners in this circus," says James. Perhaps starting with the inclusion of genetic privacy in the Protection of Personal Information Bill currently being gazetted in Parliament?

● *Malherbe is a freelance journalist.*



HUMILIATED: The public revelation of Semenya's DNA results violated our constitution and the Declaration of the Rights of Patients, says the writer.