

News

Conference Genetic privacy

The end of anonymity

Genetic technologies are revealing long-hidden identities

Chelsea Whyte

A BATTLE between billionaires over the control of country club tennis courts six years ago could shape the future of genetic privacy. That is what a rapt audience attending a conference at Harvard Law School was told on 17 May. We had gathered there to discuss the ethical and legal considerations of the rapid spread of technologies that collect, analyse and alter DNA.

Canadian businessman Harold Peerenboom and Marvel CEO Ike Perlmutter have been feuding for years, sparked by a disagreement over the management of recreation areas in their Florida neighbourhood, and fuelled by a subsequent campaign of defamatory mail anonymously sent to their local community.

Peerenboom suspected Perlmutter of sending the hate mail. To find out if this was the case, Peerenboom worked with his lawyers to get a sample of Perlmutter's DNA from a water bottle he used during a deposition. A similar approach was used to gather evidence against the suspected Golden State Killer last year, after police pinpointed a man by using a genealogy website.

In 2013, a judge ruled that Perlmutter had a reasonable right to assume his genetic information on the lip of a water bottle wouldn't be surreptitiously swiped, and that doing so deprived him of his "rights of ownership, possession, control, and privacy", according to the case documents.

The Perlmutter case changed the conventional wisdom that genetics isn't property, Jessica Roberts of the University of Houston in Texas told me at the meeting. It sets a precedent that could rein in police investigations.

It could also protect prominent people from a new kind of snooping. "It's only a matter of

time before we will see genetic paparazzi publishing genetic information on tabloid pages," says Liza Vertinsky at Emory University in Georgia. "Lawsuits will follow."

Madonna has been known to hire cleaning crews to wipe down hotel rooms she has stayed in, for

99%

of a population becomes traceable once 2 per cent have uploaded their genome sequence

fear of just this scenario. But Vertinsky says it isn't just celebrities who may be targeted, so could presidential candidates.

Vertinsky wonders how the public would respond to hearing that a candidate has genes linked to risk-taking or schizophrenia, even though having a gene for a condition doesn't necessarily mean you will develop it. Should

voters base their opinions on the possible future health of candidates? She believes it won't be long before courts have to rule on breaches of privacy like this.

The conference also considered issues that affect people beyond the rich and famous, including the erosion of anonymity, particularly when it comes to sperm donation.

Genetic ancestry tests like those from AncestryDNA and 23andMe—along with 90 or so other US companies—now make it possible to track down relatives that may never have wanted to be found.

In February, Danielle Teuscher of Portland, Oregon, submitted her 5-year-old daughter's DNA to 23andMe, and found the mother of the sperm donor she had used to conceive her child. She contacted her daughter's biological grandmother, and

Sperm donated anonymously can now be traced online

then received a letter from NW Cryobank, the sperm bank she had used, saying she had violated their donor privacy agreements.

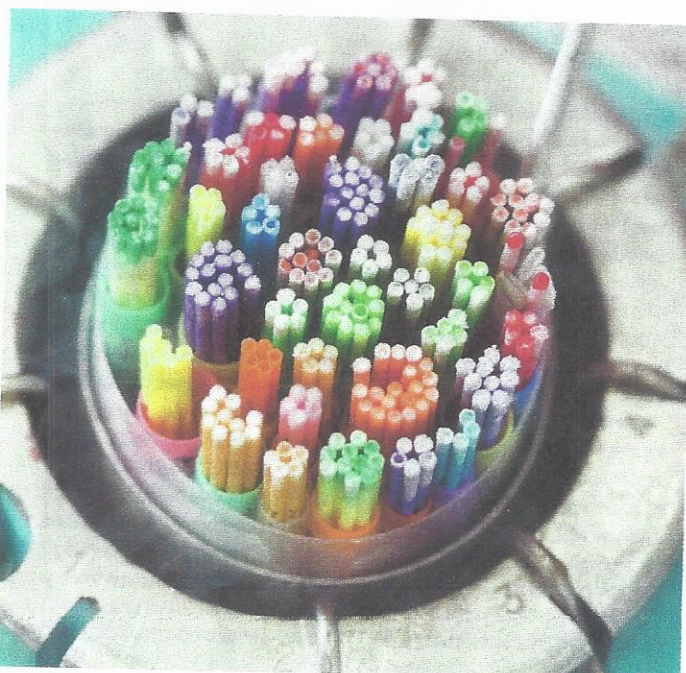
They threatened \$20,000 in penalties and rescinded access to sperm from the same donor she had purchased to conceive more children. "We know there is no anonymity, but we're still pretending there is," says Seema Mohapatra at Indiana University.

These issues extend beyond sperm donation. Kif Augustine-Adams of Brigham Young University in Utah told attendees about the revelation of a painful family secret. Her daughter's decision to take an ancestry test led to the revelation that Augustine-Adams had a sister she wasn't aware of.

It turned out that her mother became pregnant as a result of a rape, and the child had been adopted. "Washington state adoption law had offered her anonymity," she says.

This law has since changed, but some other states still promise privacy for biological mothers who have been raped. But only 2 per cent of a population needs to take a consumer ancestry test for 99 per cent to become traceable through their third cousins, meaning many such promises will soon become meaningless.

"A de facto national DNA database is on the horizon, if it's not already here," says Natalie Ram at the University of Baltimore in Maryland. Aside from a few precedents set by quirky lawsuits such as the Perlmutter case, we have almost no legal framework with which to govern its far-reaching power. ■



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