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Reactivating mitochondria seems to trigger cancer cells to commit suicide.

rest of your life to lose,” says George Annas, an expert in bioethics at Boston University School of Public Health.

And if patients can access DCA — or other unapproved drugs — there is no incentive for them to enter a clinical trial. So in terms of public health, ethicists argue, more people will be helped if access to unapproved drugs is restricted and proper trials performed.

Peter Jacobsen, an expert in ethics, health and law at the University of Michigan in Ann Arbor, doubts whether any good can come of the patients’ efforts. They are so desperate to see results, he says, that there is no way they can report unbiased results and no mechanism to ensure the reports are accurate. “I don’t trust the data,” he says. “It’s hard enough to rely on them in clinical trials, let alone this.” ■

Helen Pearson

Database targets Parsi genes

BANGALORE

A biotechnology company in Bangalore has launched a project to build a genetic, genealogical and medical database of India’s 69,000-strong Parsi community. Parsis are thought to be particularly genetically homogenous, so researchers hope to use the data to identify genes involved in disease and develop new treatments and diagnostics — in a similar way to a national genetic database already set up in Iceland.

Fleeing persecution by invading Arabs, the Parsis arrived in India from Persia 1,200 years ago, around the same time that a few hundred Vikings arrived in Iceland. They speak a unique Indian dialect and their religion forbids marriage outside the community, so they have remained relatively inbred.

“I realized four years ago that I was sitting on a goldmine or a powder keg,” says Viloo Morawala Patell, a Parsi and molecular biologist who founded the biotech company Avesthagen in 1998. Patell says she refers to a powder keg because of the fear that Parsis will soon become extinct because of inbreeding (the population has shrunk to its present size from a high of 115,000 in 1941). But like Iceland, the project could also present a commercial opportunity. In 1999, Iceland’s government licensed the genetic information from the national database to deCODE Genetics, a biomedical company that hopes to develop new cures and diagnostic kits.

Hoping to do the same for the Parsis, Patell launched the 1.25-billion-rupee (US\$30-million) project on 21 March.

She plans to create a database that holds genetic data, together with genealogical and medical histories, of at least 50,000 Parsis in five years and eventually of the entire community. Parsis already keep extensive genealogical data, says Patell, and it should be possible to reconstruct their medical records from clinics and hospitals in Mumbai, where more than 90% of Parsis live. The company’s genomics and bioinformatics facilities have been upgraded so they can sequence selected markers in



The Parsi community has a unique gene pool.

the participants’ DNA.

Avesthagen will provide the initial capital and plans to raise the rest from prosperous sections of the Parsi community and other sources. Patell declines to name potential sources, although Avesthagen already has several international collaborations, including with the French company bioMérieux for the development of diagnostic chips, US company Sequenom for the validation of genetic markers for cancers, and European drug giants AstraZeneca and Novartis.

Patell says that she has been discussing the project with prominent members of the Parsi community for four years, making the case that the information gained will directly benefit the health of the dwindling population. A council

of eminent Parsi figures will manage the project, deciding on matters such as who will own the database and who can access the data.

Vasantha Muthuswamy, deputy chief of the Indian Council of Medical Research (ICMR), says that the government has no problem with the commercialization of the community’s genetic information as long as the ICMR’s biobanking guidelines are followed. Among other things, these require informed consent and

data confidentiality — issues that overshadowed Iceland’s plans to establish a database for the health sector. “After Iceland, this has become a global issue,” Muthuswamy told *Nature*. “We have to see what kind of agreement the Parsi community signs with Avesthagen.”

Patell says that the genome analysis will focus on genetic defects common in Parsis, such as a deficiency of G6PD (glucose-6-phosphate dehydrogenase) — an enzyme that triggers the sudden destruction of red blood cells. Reduced fertility, ovarian disease, Parkinson’s, Alzheimer’s and breast cancer are other likely areas of study.

But not everyone is convinced that the project will work. Studies suggest that there has been some mixing of Parsi genes with those of other Indians. “It is a bit of a gamble,” says Indraneel Mitra, director of the Bhopal Memorial Hospital and Research Centre in India. “My feeling is that the Parsis are not as pure as Icelanders, and in any case I do not know how fruitful the Icelandic study has been.” ■

K. S. Jayaraman



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