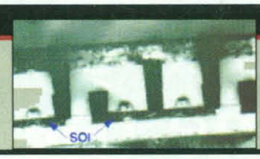

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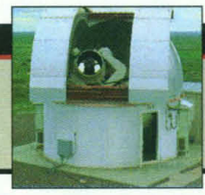
New foundation for chip design



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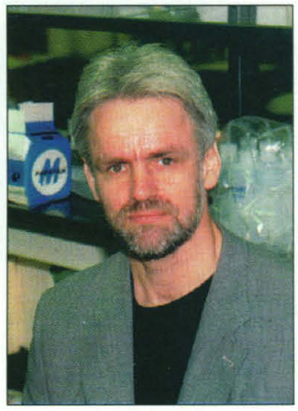
Stepped-up search for asteroids

HUMAN GENETICS

Physicians Wary of Scheme to Pool Icelanders' Genetic Data

Discord over a plan to put the health records of every citizen of Iceland into a huge database, and then grant a private company the right to analyze and market the data, has reached a new pitch. Late last month, the Icelandic Health Ministry unveiled a new bill that would make such a deal possible. Although the measure seems to have widespread public support, it has come under sharp attack from some of the people whose backing will be critical to make the scheme work: physicians and scientists. "Patients come and talk to me, and at night I'm supposed to send the information to a third party that can sell it on the world market," says Tomas Zoega, head of the Psychiatry Department of the National Hospital and chair of the Ethics Committee of the Icelandic Medical Association. "That is extremely troublesome."



"We are bringing tangible benefits to the community, and they have embraced us."

—Kari Stefansson

At the center of this simmering controversy is deCODE Genetics, a company founded in 1997 by former Harvard University geneticist Kari Stefansson. DeCODE intends to mine one of Iceland's most precious resources: the genetic composition of its people. Thanks to its isolated position and several bottlenecks that wiped out large parts of the population, the island has a remarkably homogenic gene pool, making it relatively easy to track down disease-causing mutations that might form the basis for new tests and therapies. In a deal that could be worth more than $200 million, Swiss pharmaceutical company Hoffmann-La Roche has already bought the rights to develop and market drugs resulting from genes deCODE hopes to find for a dozen disorders (*Science*, 24 October 1997, p. 566 and 13 February 1998, p. 991.)

Under the plan, deCODE would provide terminals to connect every health care station and hospital in Iceland to a central computer, into which doctors would feed data on their patients. The database would also contain the records of deceased people, which Iceland already stores in well-kept records spanning most of the century. Combined with the country's detailed genealogical records and with blood or tissue samples voluntarily donated by patients, such a database would be a powerful tool to hunt for disease genes.

The Icelandic government has embraced the plan, which could provide the island's small economy with hundreds of new high-level jobs and millions of dollars. On 31 March, the Health Ministry presented Althingi, the unicameral Icelandic parliament, with a "Health Database Bill" that would provide the legal basis for deCODE to move ahead. But the ministry was forced to withdraw the bill a month later, after strong protests from geneticists and the Icelandic Medical Association and a unanimous appeal for postponement by the staff of the University of Iceland's Faculty of Medicine. Critics complained that storing personal information without prior consent would be unethical and could result in abuse, and they attacked the idea of giving one company a monopoly on what they see as the collective property of a whole nation. Some academics also feared the scheme would hamper their own studies.

The Health Ministry rewrote the bill and unveiled a new version on 31 July that addresses some of the concerns. For instance, individuals can now ask for their data to be included in such a way that the information could never be traced back to them, although they will have to take the initiative themselves. And an independent committee will oversee the whole project. But Zoega says the bill is still unacceptable to many physicians.

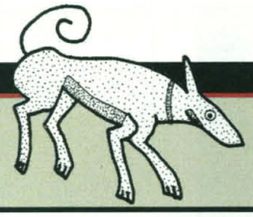
For example, the scheme would protect Icelandic citizens' privacy by stripping their identity from their records and replacing it with a code before the records are entered into the database. But, says geneticist Jorunn Eyfjord of the Icelandic Cancer Society's research lab, in a country of just over 270,000 people, it would be "naïve" to think this would suffice. A few items of data—such as a person's profession, family relations, and the 5-year interval in which he or she was born—would be enough to give away that person's identity, she says. Others have expressed concern that the data may fall into the wrong hands. The two main trade unions, for instance, worry that employers might try to gather data about their workers.

MORGUNBLADID

"The nature of the proposition sounds very Orwellian," admits deCODE CEO Stefansson. "So it's very easy to have sort of a visceral reaction to it." Stefansson also concedes that no database could ever be 100% secure. "But the fact of the matter is that every single piece of information that would be anonymous in this database is now available under name in the hospitals and health care stations." The net outcome of the law, he says, would be to diminish, not increase, access to personal information.

To alleviate fears about academic freedom, the new bill grants Icelandic scientists access to the database for noncommercial research. Applications will be handled by a three-person committee, one member to be nominated by the company, one by the health ministry, and one by the university. But the bill gives deCODE exclusive rights to market the data for a period of 12 years. That's an absolute necessity to make the project viable, says Stefansson: "It would be an extremely difficult business proposition without the exclusivity."

But others maintain that it's wrong to give a single private company such a monopoly. Just last week, the issue was sharpened when Reykjavik engineer and businessman Tryggvi Petursson announced that, together with two Icelandic biomedical scientists working in the United States, he will set up a company called UVS that will challenge deCODE's hegemony. UVS wants to cooperate with the



FOCUS

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Tussle over Albanian archaeological site

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The 3-decade battle over salt and blood pressure

Icelandic Cancer Society in tracking down cancer genes. Although the company says it could work without the health care system data if it had to, its entry into the field is "a godsend," says Sigurdur Gudmundsson, chair of the National Bioethics Committee, "because it will make the discussion about monopoly much more focused and real."

So far, the bill's opponents have found little support among the general public. In a Gallup poll commissioned by deCODE, 82% of the respondents said they were in favor of the database, and 51% believed that deCODE would be the best party to develop it. "We are bringing tangible benefits to the community, and they have embraced us," says Stefansson. Critics say, however, that the public has been lured by a slick public relations campaign and unrealistic expectations. DeCODE promises that Icelanders will get any drugs or diagnostics based on their genes for free during the patent period—a promise Eyfjord calls "a joke. ... How many drugs do you think are going to be developed, and how many people will really benefit from that?"

But members of parliament, too, seem more impressed with the benefits of the plan than with its possible downsides. "Judging from their initial comments," says Gudmundsson, "they love it. I'm almost certain that [the new bill] will fly through parliament." But deCODE will still need to win over the medical community. Says Zoega: "If we do not cooperate, it simply will not work."

–MARTIN ENSERINK

Martin Enserink is a science writer in Amsterdam.

SOLAR PHYSICS

Hopes Rise After SOHO Calls Home

Earlier this week, ground controllers reestablished full radio contact with the Solar and Heliospheric Observatory (SOHO). Many had given SOHO up for lost after a series of command errors caused it to spin out of control and fall silent early on 25 June, but the renewed dialogue with the satellite has raised hopes of bringing the $1 billion spacecraft back to life.

The first useful transmissions from SOHO carried readings from dozens of onboard temperature and voltage sensors. The message they conveyed is dryly summarized by Francis C. Vandenbussche, the SOHO spacecraft manager from the European Space Agency (ESA) who heads the recovery team: "It's a little bit chilly." That chill, suggesting frozen fuel tanks, is to be expected: The spacecraft had been tumbling without power for 6 weeks before controllers achieved sporadic contact on 3 August. Full contact came just under a week later, after controllers managed to recharge an onboard battery. Now an expert team of engineers will begin evaluating data from many kinds of sensors on SOHO and come up with a strategy to bring the spacecraft back from the brink. "This was a big, big step" toward recovery, says Bernhard Fleck, the SOHO project scientist for ESA, which operates the craft jointly with NASA. "You can imagine the relief."

ESA/NASA

Cool signal. SOHO radioed temperature data indicating its fuel tanks are frozen.

The debacle on 25 June occurred when SOHO went into a spin that left its solar panels unable to collect sunlight and generate power. Those first sporadic responses on 3 August meant that the panels were in a position to collect some sunlight again. But controllers received only a so-called carrier signal from the spacecraft—"analogous to lifting your phone and getting a dial tone," says Joseph Gurman, the SOHO project scientist for NASA. Later, 10- to 15-second bursts of signals arrived carrying slight modulations, which encoded information that controllers were initially unable to read.

The reestablishment of partial contact was soon accompanied by a second bit of good news: A separate effort, in which radio waves were bounced off SOHO using the 305-meter dish at Arecibo, Puerto Rico, determined a precise spin rate for the craft of one rotation in about 53 seconds. "That's good from a structural point of view," says Gurman. "A bad number might have been 10 times that," or a rotation every 5 seconds. The information also told engineers why the carrier signal turned on and off: Solar panels face the sun only during half a rotation, and then the spacecraft lost power and went silent again. On 8 August, controllers told SOHO to use the power from its panels to charge up one of its batteries. The operation succeeded, permitting minutes-long establishment of full communication with SOHO by the following day, says Gurman.

As the expert team, drawn from engineers at ESA and Matra Marconi Space—the company that built SOHO—plots the next moves in the recovery mission, it will face several key decisions. A critical judgment will involve the strategy for gradually returning power to SOHO's many heaters, which normally keep the craft at about room temperature. That would allow controllers to thaw the tank of hydrazine that fuels SOHO's thrusters—which would have to be fired to stop the spin. But the operation could be tricky; it will require a close knowledge of structural details combined with thermal and other information so that the warm-up does not damage frozen components. That effort "is still missing some pieces of the puzzle," says Vandenbussche. Over the next couple of weeks, he hopes the signals streaming from SOHO will provide those pieces.

–JAMES GLANZ

ASTROPHYSICS

Ultraenergetic Particles Slip Past Cosmic Cutoff

TOKYO—Every so often, a cosmic ray slams into the atmosphere packing 100 million times the energies reached in the world's largest particle accelerators—the energy of a brick falling from a table packed into a single subatomic particle. Until recently all the cosmic ray facilities worldwide had detected a total of just three of these fantastically energetic particles, so small a number that they might have been the few outliers at the very top of the cosmic ray energy spectrum. Now, however, the Japan-based Akeno Giant Air Shower Array (AGASA) collaborat.ion has recorded a further handful of ultraenergetic events—enough to conclude that the upper limit to cosmic ray energies is not yet in sight. And researchers expect more such sightings from new detectors scheduled to come on line in the next few years.

"It's pretty darn exciting," says James Cronin, a physicist at the University of Chicago, because these particles are somehow evading a cosmic speed trap. A cosmic