CLINICAL RESEARCH

## Company Plans to Bank Human DNA Profiles

For years biotech companies have promised a new type of medicine with drugs tailor-made to a person's genetic profile. But proponents of this concept, called pharmacogenomics, know it can't move forward until several obstacles, both scientific and ethical, are cleared. Key among those is people's fear that their genetic data won't be kept confidential. Last week, a for-profit group—the First Genetic Trust Inc. of Deerfield Park, Illinois—announced a plan intended to alleviate those concerns.

The company hopes to act as an intermediary between patients and researchers. Individuals would let the company store their genetic information in its confidential database for use in clinical research, and the company would communicate with them over the Internet to ensure that informed consent is given for any use of the data. First Genetic Trust has teamed up with the Memorial Sloan-Kettering Cancer Center in New York City to test the scheme.

CEO Arthur Holden says his idea is to create "a structure with Swiss bank–grade security" to hold confidential deposits of genetic information about research subjects and other patients. Holden is also chair of The SNP Consortium, a nonprofit outfit financed in part by pharmaceutical companies to collect data on variations in the human genome that could be used to track down disease genes (*Science*, 16 April 1999, p. 406). The new project, Holden says, raised about $14 million last year from two venture capital firms—Venrock Associates, a Rockefeller family group in New York City, and Arch Venture Partners of Chicago. IBM is also a "strategic partner."

**Private banker.** Arthur Holden promises "Swiss bank–grade security."

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Initially, the trust would retain just DNA information, says a spokesperson, but later it might also keep records used in clinical care. The trust would give patients detailed information about the risks and benefits of the research projects they're being asked to join. It would also enable researchers to contact patients much later and obtain consent for follow-up research studies or arrange for follow-up medical treatment.

Holden insists that the patients would control access to their own data. The company would use the Internet to stay in touch, he says—updating patients on research findings, seeking specific consent for new uses of the data, possibly contacting patients with new requests, and distributing coded files to scientists. Initially, the research sponsors—mainly pharmaceutical companies—would pay for the cost of this record keeping, says company spokesperson Mary Prescott. She argues that sponsors of clinical trials would be glad to turn the responsibility for managing patient consent and confidentiality to a third party.

The concept will get its first test at Sloan-Kettering, where Kenneth Offit, chief of clinical genetics, is drawing up a research protocol. Offit was not available for comment, but according to one company executive, the protocol involves genetic counseling for about 50 women who carry *BRCA1* or *BRCA2* genetic mutations and are at high risk for breast cancer. First Genetic Trust is also negotiating to be part of several other large research projects elsewhere.

Creating a private institution to act as a third-party broker of genetic information is "an interesting concept," says Mark Sobel, past president of the American Society for Investigative Pathology. Sobel, a pathologist at the National Cancer Institute who has been monitoring federal genetic privacy policies for several years, says he likes the third-party data trust if it relieves researchers of paperwork. But Sobel warns that the scheme must pass muster before local ethics panels, known as Institutional Review Boards, and must offer patients "more than just a check-off box" in seeking their consent.

Robert Gellman, a Washington, D.C., consultant on privacy issues, is more skeptical of the plan, saying he sees "nothing but problems." Noting that the trust's policies are undefined, Gellman worries that, once they are spelled out, they could turn out to be more complex than the present system of controlling access to medical data, which does not require researchers who are using anonymous data to seek the consent of each subject.

–ELIOT MARSHALL

CANCER RESEARCH

## U.K. Cancer Funders May Unite

**CAMBRIDGE, U.K.**—A giant funding agency akin to the U.S. National Cancer Institute may be in store for British cancer research. Trustees of the two largest private cancer charities in Britain—the Imperial Cancer Research Fund (ICRF) and the Cancer Research Campaign (CRC)—met last week to discuss future collaboration plans, including a full merger.

The organizations stress that the talks are at an "exploratory" stage, and that several levels of collaboration short of a full merger are also being considered—including launching joint-venture initiatives and avoiding duplication of effort. A merger would improve efficiency, says ICRF director-general Paul Nurse: "Facilities are very expensive, and the best solution may be to pool our resources." In addition, one national organization would be better able to train young researchers and would give cancer research a stronger voice, Nurse says.

Currently, there's little overlap in what the charities do: The ICRF, with an annual research expenditure of $96 million, conducts research at its main institute in London and at its own clinical research units throughout the U.K., while the CRC acts mainly as a granting agency that spends about $94 million a year on research projects across the country.

Scientists welcomed the possible merger. "There has always been a balance between competition and duplication, and a major effect of any merger will be increased coordination," says David Lane, head of a research unit into the molecular basis of human cancer at the University of Dundee, who gets funding from the CRC. But Lane worries that a combined charity may not rake in as many donations as two separate ones. "So long as the science itself is done in a collaborative manner, it doesn't matter if there are one or two or however many organizations. … The aim must be to make a merged body that is more than the sum of its parts," says Sir Walter Bodmer, an oncologist at the University of Oxford and former director-general of the ICRF.

A preliminary report about the road ahead will be presented to the organizations' councils later this month. A final decision is not expected until later this year. –JOHN PICKRELL