

safety of these drugs as expressed in this program had more to do with her long-standing bias against the [HPB] and her superiors than it had to do with public safety."

Cunningham concluded that the "nasty little story," which "wasn't an important story at all," caused "devastating damage to Dr. Leenen."

Asked how the program had affected him professionally, Leenen responded: "It created a glass ceiling for me as far as Canada is concerned. I can see higher but I cannot go higher." He hopes the court ruling, and particularly the size of the judgement, will change this.

He remains bitter that the CBC refused to settle the matter 4 years ago with an apology and payment of \$10 000. "And the \$10 000 was negotiable," says Leenen.

His lawyer says the CBC should have taken that offer. "I told Frans in 1996 that this was the strongest libel suit I had ever seen," says Dearden. "But the CBC played dirty from the start."

Leenen concludes that "any time you take on the CBC, you're David because it is Goliath. In dealing with *the fifth estate*, you're confronting an organization that takes a scorched-earth approach to defending libel actions, backed by the financial resources of Canadian taxpayers."

Now, he simply wants the matter to end. "The CBC must stop trying to defend the indefensible," he says.

He shouldn't hold his breath. Spokesperson Ruth-Ellen Soles says the CBC is currently reviewing the Leenen decision and "considering its options." It has not issued an apology to him, and has already filed an appeal over the Myers' ruling. Meanwhile, the interest clock keeps ticking. Dearden says he will ask that an additional \$250 000 be added to Leenen's damages to cover interest on the award.

David Bazay, the CBC ombudsman, says his office does not comment on cases that are before the courts. "We have a policy," he says. "You can come here or you can go before the courts, but not both. I usually inform complainants they should be aware that if legal action is taken, we stand aside."

Cunningham, meanwhile, said that he could not stand aside. "The CBC has enormous power and an incredible ability to inflict damage . . . In light of the defendants' reprehensible conduct, I have concluded that a message must be sent. Parasitic sensationalists should not be allowed to prey upon society's obsession with scandal and to reap personal benefit from their irresponsible actions."

Patrick Sullivan is News and Features Editor at CMAJ.

Reference

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Benefits of genetic research must be shared, international genome organization warns

Heather Kent

Although the race to complete sequencing of the human genome is nearing completion, attempts to deal with ethical and other concerns arising from the huge project are only beginning. Scientists attending the Human Genome 2000 meeting in Vancouver this April appeared to realize this, and responded by approving a statement on the need to share benefits arising from their groundbreaking research.

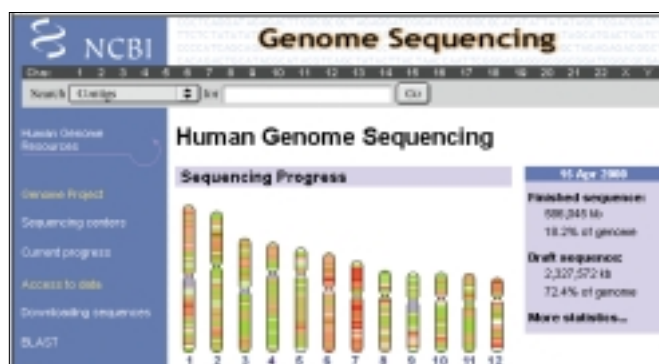
Although they agreed that private-sector involvement is needed to speed product development and that patenting helps encourage research, they are also worried about the misuse of data and about attempts to patent and commercialize genes, thus depriving others of the potential benefits. For example, Celera Genomics Group in the US has applied for 300 patents relating to its DNA-related research. It is the private company competing with the publicly funded Human Genome Project to complete sequencing of human DNA. The company recently announced that it had decoded the

human genetic sequence for the first time, although what it actually has are raw data from 1 person, which it is now starting to assemble like pieces of a jigsaw puzzle.

The project has been controversial because Celera obtained about half its data from publicly available genome information, yet charges people for access to it. (Data from the publicly funded genome project are available at www.ncbi.nlm.nih.gov/genome/seq, where they are updated every 24 hours. A Web-based genome browser for looking at chromosomes and gene maps will be ready by next month.)

To obtain its patents, Celera has to demonstrate the usefulness of the genes. "If the application potential is not there, there is no incentive to patent," says Dr. Mark Adam, Celera's CEO.

Dr. Gert-Jan van Ommen, past president of the Human Genome Organization (HUGO), would like to see the 20 000 patents already granted "in error" rescinded because



proof of the genes' function has not yet been demonstrated. "They are patenting the rainbow," he said.

Timothy Caulfield, research director at the University of Alberta's Health Law Institute, says most patent offices are "ill equipped to deal with social and ethical issues around patenting [of genes]." Dr. Michael Hayden, director of Vancouver's Centre for Molecular Medicine and Therapeutics and the conference chair, admitted that the premature granting of patents would result in "a huge disincentive to research." However, he also says that it would be "naïve" to expect patents to be revoked. Meanwhile, the US Patent Office is raising the bar for patent applications, and Hayden expects that now patents are unlikely to be granted based on raw genetic data.

HUGO, which was established in 1989 to coordinate global genomic research and now represents about 50 countries, responded to these wide-ranging global concerns by issuing a statement on benefit sharing during the Vancouver meeting.

HUGO says:

- all humanity should share in and have access to the

benefits of genetic research;

- benefits should not be limited to the individuals who participated in such research;
- there should be prior discussion with groups or communities on the issue of benefit sharing;
- even in the absence of profits, immediate health benefits as determined by community needs could be provided;
- at a minimum, all research participants should receive information about general research outcomes and an indication of appreciation; and
- profit-making entities should dedicate a percentage (1%-3%) of their annual net profit to health care infrastructure or humanitarian efforts.

While releasing the statement on benefit sharing, Dr. Bartha Knoppers, a University of Montreal bioethicist who sits on HUGO's Ethical, Legal and Social Issues Committee, said: "This complex legal and ethical subject area requires intense deliberation by scientists, lawyers and industry." Knoppers says that although HUGO lacks legal force, its statement on benefit sharing is designed to "get people talking."

"The challenge is how to implement HUGO's recommendations," says Hayden.

Social concerns, such as possible discrimination for insurance purposes, eugenics and respect for cultural values, have been addressed by the World Health Organization, which recently completed a comprehensive report designed to prevent exploitation of developing countries. Dr. Lap-Chee Tsui, president of HUGO and geneticist-in-chief at Toronto's Hospital for Sick Children, says that legislation to prevent discrimination by employers and insurance companies is "urgently needed."

Heather Kent is a Vancouver journalist.

Comprehensive, genome-based health care not far off

The original timetable for completing sequencing of the human genome by 2005 seemed ambitious when it was announced, but with the "prodigious output" of about 1200 researchers from around the world, more than 80% of the genome has been decoded and a full working draft will be available by this summer. Dr. Francis Collins, director of the US National Genetic Research Institute, says most diseases are now believed to have a genetic component. He anticipates

that the genetic causes of the majority of common diseases will be known within the next 5 years.

He whimsically predicted a future in which successful gene therapy and legislated genetic privacy are in place by 2010, with gene-based designer drugs following by 2020. By 2030, he foresees a full computer model of the human cell replacing laboratory experiments, and the identification of genes responsible for the aging process. Fast forward to 2040, Collins says that "com-

prehensive, genomic-based health care" will be routine, with individualized preventive gene therapy and an average life span of 90 years.

On a less positive note, he warns of worsening inequities separating the developed and developing worlds and of a serious debate about humans "taking charge of their own evolution." Those involved in genetics research have a major responsibility to ensure that their work benefits as many people as possible, he says.