

Ex-nurse becomes first woman to head MMA

The first female president of the Manitoba Medical Association (MMA) has worked both sides of the hospital hallway, first as a nurse at the Grace General Hospital in Winnipeg and now as a general practitioner at University of Manitoba Health Services. "I decided to become a doctor because I wanted to know more about medicine," says Dr. Lorraine Hilderman, who returned to Winnipeg to attend medical school in 1980, leaving a nursing job in Omaha, Nebraska.

"As a former nurse, I had a slight advantage over some of my fellow students in that I knew the medical lingo," says Hilderman. "Med students really have a tough time deciphering it."

Now, as the new MMA president, Hilderman will have to unravel a tangled web of problems that besiege Manitoba's doctors. One of her priorities is to address the problem of physician retention in a province where 66% of family practice residents and at least as many specialists leave upon finishing their residencies.



Hilderman: Manitoba has to become more competitive to attract doctors

"It costs taxpayers \$100 000 to train a family practitioner and many times that to train a specialist," says Hilderman. "We have to become competitive with other provinces if we are going to keep doctors in Manitoba."

Although the MMA recently negotiated 2 arbitration awards with the government, negotiations with Manitoba Health continue concerning at least 26 separate disputes. Hilderman says these range from the funding of department heads to providing medical services such as dialysis in rural and northern Manitoba.

Hilderman is known at Manitoba Health for her tough negotiating skills when a contract is on the table. "I'm not a pushover,"

she says, "but I'm more comfortable fighting for a contract in a boardroom than I am speaking to the media or to a large group of people."

"I don't think of myself as someone special," she adds. "I'm just a doctor doing my job." — *David Square, Winnipeg*

British health care system ailing, survey finds

The public health care system is not doing well and new treatments may be needed to revive it, according to more than 600 residents interviewed in a recent Gallup poll. However, the system in question is not Canada's, but the UK's National Health Service (NHS).

Eighty-five percent of respondents interviewed in the poll, conducted for the *Daily Telegraph*, said Britain's health care system was "in somewhat failing health" or doing "very poorly indeed." Only 2% said it was in "peak condition."

About 1 in 8 respondents felt that the British system can carry on nicely as it currently exists, but 85% felt that

the system is unlikely to survive without a large infusion of cash. There was less agreement about where that money should come from. Surprisingly, a significant majority (67%) said they would be prepared to pay a hefty tax increase — \$375 a year — if they could be assured the money was going solely to the NHS.

When asked if money from the national lottery should go to health care, respondents were more divided, although 62% said some or all of the money should go to the NHS.

There was a noticeable split over the question of collaboration with the private sector. Although 58% of respondents thought there should be "a

fair amount" or "a great deal" of collaboration between the public and private sectors, 36% did not look upon such a relationship favourably.

When asked where the money should come from to fund the NHS, 83% of respondents said the funds should come "almost entirely" from tax revenue. Sound familiar? — *Donalee Moulton, Halifax*

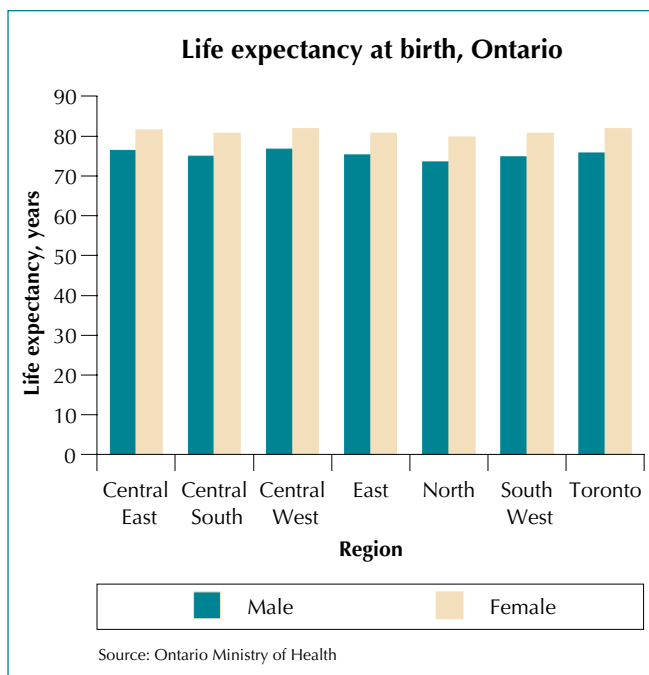
Prevention must be health focus in Northern Ontario

Residents of Northern Ontario tend to be more overweight, consume more alcohol and get in more accidents than their counterparts in the south, a comprehensive health-status report prepared by a partnership of 6 provincial health units states. Northern Ontario's combination of low life expectancy and high mortality rates, combined with an increased incidence of risk factors such as smoking and alcohol use, requires a major emphasis on preventing chronic disease, the authors said.

"This congruency speaks to the need to target preventive programs to specific conditions such as smoking, obesity, lack of physical activity, alcohol use and activities at high risk for injury," concluded the 210-page Report of the Health Status of the Residents of Ontario. "Interventions aimed at reducing the rate of risk factors [such as smoking] will reduce the rates of many diseases, such as heart disease, lung cancer, chronic lung disease and many other forms of cancer."

The report found that the age-standardized mortality rate for Northern Ontario females is 607.5 per 100 000, 27% higher than the rate of 479.8 found in Toronto. The rate for Northern Ontario males (971.9 per 100 000) was 25% higher than for their Toronto counterparts. Life expectancy for females is 79.8 years in the North, compared with 81.8 for Toronto females. A Northern male can expect to live 73.5 years, compared with 75.7 for his counterpart in Toronto.

The study also found that Ontarians are generally as healthy as other Canadians, with similar life expectancy and mortality rates. The province's highest rates of communica-



ble diseases are in Toronto, which reported more than half of Ontario's cases of AIDS, tuberculosis and gonorrhoea.

Meanwhile, lung cancer threatens to overtake breast cancer as a cause of death among Ontario women, pointing to a need for smoking prevention programs aimed at young women. — *David Helwig*, London, Ont.

Nova Scotia slashes health care spending

Nova Scotians are learning to live with a new provincial budget that, while not as detrimental to their health as the government had intimated, is still a bitter pill to swallow. Overall, the health care budget has been cut by 4.7%, while hospitals like the Queen Elizabeth II Health Sciences Centre in Halifax will be taking a 5.5% hit. This is on top of a 3.2% reduction the hospital faced at the beginning of this year. "Our challenge will be to maintain safe, accessible and quality patient care when wait lists are already long and beds running at full capacity," says Bob Smith, the QE II's president and CEO.

Seniors are also finding it hard to balance their health care needs with

their cheque books. User fees for Pharmacare, the provincial drug plan for seniors, have jumped 20% — an average increase of about \$5 per prescription. As well, the annual copayment fee rose to \$350 from \$200. Home care costs have also risen \$2 an hour, from \$6 to \$8. In addition, taking an ambulance now costs \$85, as opposed to the previous fee of either \$60 or \$80. These new fees, along with others outlined in the budget, are expected to save the government about \$12 million this fiscal year.

Nova Scotia, 1 of only 3 provinces without a balanced budget, is trying to rein in health care spending, which has risen by almost 38% in the last 3 years to its current level of \$1.8 billion annu-

ally. As part of the reining-in process, 600 jobs are being eliminated. Health Minister Jamie Muir hopes that administrative positions will be the ones to go and that patient care will not be directly affected.

Although the cuts to health care may hurt, pumping more money into the ailing system is not the answer, says Finance Minister Neil LeBlanc. "If money alone were the answer to good health care, Nova Scotians would have the best health care in the country. Last year, Nova Scotia spent more per capita on public health care than any other province."

That is unlikely to be the case this year. — *Donalee Moulton*, Halifax

Birth of Nova Scotia midwifery program delayed

After spending months drafting new legislation that would make midwifery a self-regulating profession, the Nova Scotia Department of Health has put its legislative plans on the back burner. Although self-regulation would allow a midwife's services to be covered under the province's medicare plan, it would also require that an effective self-disciplinary process be put in place. According to the minister of health, there are only 4 midwives in all of Nova Scotia, an insufficient number for self-disciplinary action.

"If you had 4 people it would be very difficult," says Health Minister Jamie Muir. "If there was a single disciplinary matter, it would mean there would only be 3 people left to deal with it."

Although the government has scrapped its plans to regulate midwifery, the issue is still on the table. In response to the health minister's announcement, the Association of Nova Scotia Midwives called for a meeting

with Muir. That meeting, described as "encouraging" by president Carrie Harlow, leaves the door open for future negotiations.

Last year a report entitled Recommendations for the Regulation and Implementation of Midwifery in Nova Scotia was released by the provincial government. That report, compiled after a year of research and consultation, recommended that midwifery be legally recognized as an autonomous, self-regulated primary health care profession and included as an insured service. The report also recommended that the government financially support the training of midwives in the same way the training of other health care professionals is supported. It also called for the establishment of a college of midwives in the province.

Although not currently recognized as a health procedure that can be billed under medicare, midwifery is recognized as a legal procedure in Nova Scotia. — *Donalee Moulton, Halifax*

One of medicine's most famous ORs now a museum

Thirty-three years ago, in a small South African operating theatre in what had once been a barn, an operating room team came together and changed the way medicine is practised. The team, led by Dr. Christiaan Barnard, performed the world's first heart transplant on Louis Washkansky, a 55-year-old grocer. The donor was a 25-year-old woman, Denise Darvall. Washkansky lived for 18 days after the historic operation, but died after developing pneumonia; his new heart beat strongly until the end.

Today, the Groote Schuur Hospital in Cape Town, where Barnard performed that first human heart transplant after perfecting his technique on dogs and baboons, is a thriving facility that treats patients from South Africa and beyond. The site originally became

home to South Africa's first medical school in 1912, with the hospital opening 26 years later.

Today, the operating theatre where Barnard and his team worked has been transformed into a museum, where visitors can transport themselves back to Dec. 3, 1967, when the operation was performed.

Barnard, who recently announced that he is leaving South Africa after 77 years, did not believe in putting patients through treatments that were not going to make them feel better. "The prime goal," he said, "is to alleviate suffering, and not to prolong life. And if your treatment does not alleviate suffering, but only prolongs life, that treatment should be stopped." — *Donalee Moulton, Cape Town*

Health Canada sounds warning over St. John's wort

Health Canada is warning physicians that a popular herbal remedy for depression could "seriously alter or diminish the effectiveness" of prescription medications.

A study conducted by the National Institutes of Health in Maryland found that St. John's wort (*Hypericum perforatum*) significantly decreased the presence of indinavir, a protease inhibitor used to treat HIV infection, in the bloodstream. The study found that St. John's wort decreased plasma concentrations of indinavir, possibly by inducing the cytochrome P450 metabolic pathway.

Although the study (*Lancet* 2000;355:547-8) referred only to indinavir, officials at both the US Food and Drug Administration and Health Canada are urging patients taking St. John's wort concurrently with any retroviral drug to consult their physician. In a letter to physicians, Health Canada also warns that St. John's wort may affect the metabolism of a variety of prescription drugs, including anti-epilepsy agents, oral contraceptives and immunosuppressant, antidepressant and anticoagulant drugs.

"Although drug interaction studies with St. John's wort are not available for antiretroviral agents other than indinavir, the possibility of significant decreases in the blood concentrations of all of the currently marketed HIV-1 protease inhibitors should be considered," warned the letter.

Patients have also developed "serotonin syndrome" by using St. John's wort in combination with conventional antidepressants. The syndrome is characterized by tremors, headaches and restlessness. — *Steven Wharry, CMAJ*

Screening program lets Alberta test newborns' hearing

Alberta is spending \$1 million to implement a province-wide hearing screening program this fall. "For the first time, there is large-scale recognition that this is an important problem," says Dr. Joseph Dort, associate professor of surgery at the University of Calgary, who created the Universal Newborn Hearing Program.

About 6 of every 1000 infants born in North America have some form of hearing loss, which means that more than 2000 Canadian babies are born annually with the problem. It can range from fluid in the ear, which disappears quickly, to severe deafness. About 50% of these infants experience permanent hearing loss, says Dort, but only about one-third of these cases are detected.

Dort says hearing loss is often a "silent problem," and solid research data have only recently become available. Dort says the problem has been neglected in Canada, but



Frontline photo

Dr. Joseph Dort looks on as Dr. David Brown performs a hearing test on Hayden Weber, who is being held by his mother, Denise.

about 22 American states now have universal screening programs in place. Research already indicates that if hearing loss is treated before babies reach 6 months of age, their speech and language often develop normally. Currently, says Dort, most of the children he sees are older than 2.

Epidemiologic management of Dort's project is more daunting than the medical challenges. He is now working on data management and the logistics of implementing the program throughout Alberta's health districts, which have differing needs.

His initial goal is to test 85% of the province's newborns. The test takes only a few minutes and can be administered by nurses, audiologists and trained volunteers. Positive tests will be followed up with repeat tests, and auditory brain stem response tests if needed. — Heather Kent, Vancouver

New Brunswick's limits on physician resources ruled constitutional

It took 7 years for New Brunswick doctors to get their day in court but only 10 days for a judge to determine that the provincial government did not infringe upon the constitutional rights of physicians when it introduced a physicians' resource management plan in 1992. Just 10 days after hearing the evidence — and 2 months before a decision was expected — Court of Queen's Bench Justice Hugh McLellan ruled that the "legislature may on its own initiative take drastic action to change medicare."

The Professional Association of Residents in the Maritime Provinces (PARI-MP) and 4 New Brunswick physicians had accused the government of violating Canada's Charter of Rights and Freedoms in 4 ways: restricting doctors' mobility, infringing on the concept of liberty as described in the charter, not allowing for free association and discriminating on the basis of sex.

Under the province's 1992 physician resource plan, New Brunswick was divided into 7 health regions, each with a cap on the number of doctors allowed to practise (see *CMAJ* 2000;162[8]:1186). Since it was introduced, the province has experienced one of Canada's most severe physician shortages. At present there are about 50 unfilled positions; simply to reach the national per capita average, New Brunswick would need to attract another 300 doctors.

PARI-MP has already announced that it will appeal McLellan's ruling. "It's a matter of fighting legislation that we feel is unjust," says PARI-MP Executive Director Sandy Carew Flemming. "We'll take it as far as we can [because] this has such national significance for all physicians in practice."

Although McLellan did find that the New Brunswick government's plan "has sharply reduced the rate of growth of the number of physicians in the province and makes it very difficult for hospitals to recruit physicians in new specialties," he concluded that there were no charter violations.

Carew Flemming says the judge may have misunderstood the issue of mobility, the primary concern. "We feel the judge missed the point. It wasn't new physicians inside New Brunswick versus new physicians outside New Brunswick. The discrimination exists between all new physicians and those physicians currently practising in New Brunswick. He's comparing the wrong groups."

Clearly, though, the judge was saying that the government has the right to make policy and implement programs, even though they may be restrictive. "Judges," McLellan noted in his 18-page written decision, "do not make the difficult choices on taxation levels, public spending, public policies or legal reform. Those matters are all within the respective jurisdictions of the legislature and Parliament." — Donalee Moulton, Halifax

On the Net

Helping patients untangle a Web of misinformation

Patients who once brought a friend or relative to an examination now show up with reams of data pulled off the Web. For some physicians, translating this information into practical knowledge is becoming a big part of their daily job.

Now there are Web sites to help both patient and doctor deal with this challenge. One site, Now You Have a Diagnosis: What's Next? (www.ahrq.gov/consumer/diaginfo)



.htm), walks patients through the process of finding reliable medical information on the Web and then understanding it. Consider it a user-friendly roadmap for patients.

The site was created by the US-based Healthcare Research and Quality Agency (HRQA) and the Kanter Family Foundation. It takes patients from the point of diagnosis and attempts to give them the skills to find and synthesize information and reach decisions about their medical situation.

One section explains how medical research is actually conducted and why the 6-pm newscast may not be the most reliable source for information about it. The site offers a step-by-step process for patients to follow in order to find quality medical information and warns against the shams they will come across.

“Genuine medical miracles are few and far between,” states the guide. “Beware of any drugs or treatments that make big claims. Not all information is objective and honest. If you are not sure about any treatment you find discussed on the Internet, ask your doctor or other health care provider about it.”

In this same spirit, the US Federal Trade Commission has created a site, Virtual “Treatments” Can Be Real-World Deceptions, that lists words and phrases that can indicate phony, exaggerated or unproven claims (www.ftc.gov/bcp/conline/pubs/alerts/mrclart.htm).

Once patients have completed their research and understand their condition, the HRQA site lays out a simple method for discussing it with their physician. It suggests making a list of questions to ask the doctor and encourages patients to take an active role in any treatment planning.

Because these are American sites, some of the discussion is not relevant to Canadians. Overall, though, they are good starting points for patients (and for their physicians) who want to gain a better understanding of what the Internet has to offer both of them. — *Michael O'Reilly, mike@oreilly.net*

Quebec doubles its prescription premiums

Miriam Morris, a Quebec senior citizen living on a small pension, is furious that her drug insurance premiums are doubling in price. “The seniors can’t do it,” says Morris. “It’s just impossible. They should run it like they did before.”

Quebeckers who don’t have drug coverage at work must pay a tax “premium” of up to \$175 annually, plus a deductible at the pharmacy. Under the new plan, the maximum premium will double to \$350 and the deductible will increase from \$8.33 a month to \$16.67. How much each person pays is determined by a complicated sliding scale. Only people earning less than \$10 750 a year are exempt; Statistics Canada places the urban poverty line at \$17 571. The province announced the increase in May in an effort to make its drug plan self-financing.

But some people say the new system penalizes the poor. Jennifer Auchinleck, a community organizer who is fighting the increase, would like to see low-income families receive



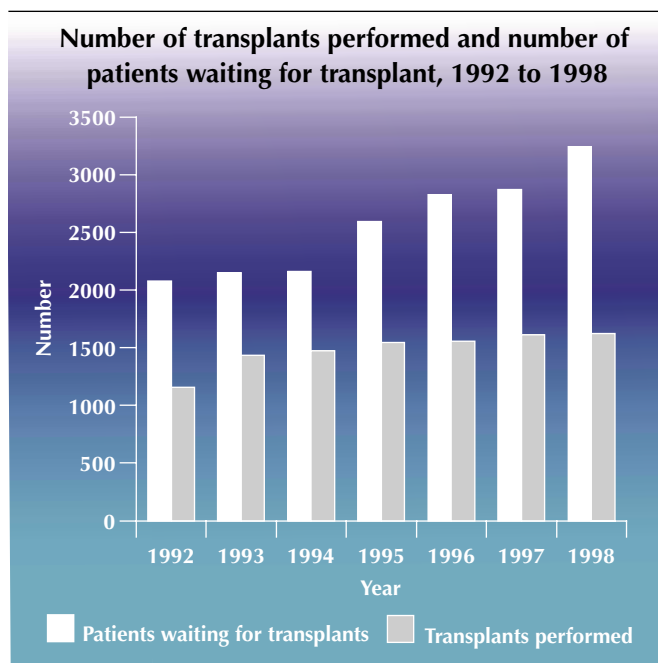
their medications free. And Dr. Paul Saba, president of the Coalition of Physicians for Social Justice, says there are alternatives to “downloading the costs” to taxpayers. He suggests that the province negotiate better drug prices with the pharmaceutical industry and change its hands-off approach to the federal drug patent law, thereby allowing generic competition into the market sooner. “If Quebec came to the national average of prescriptions of generics, they’d save \$70 million,” said Saba, who also thinks doctors write too many prescriptions. “The government could make up to \$400 million in savings by increasing the use of generics and educating physicians.” — *Susan Pinker, Montreal*

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Pulse

Transplant queues grow as donor numbers wane

Figures released recently by the Canadian Institute for Health Information (CIHI) indicate that the national organ donation rate dropped 5% between 1997 and 1998,



while the unmet demand for organs jumped by 13%.

CIHI data indicate that the rate of cadaveric donations was 13.7 per million population in 1998, and 14.4 the year before. Saskatchewan had the highest donation rate per million (21.4), while British Columbia (9.0) and the Atlantic region (9.3) had the lowest rates. (For a person to qualify as a cadaveric donor, the donation must originate in Canada, with at least one solid organ being used for transplantation.)

The average age of organ donors rose from 37 in 1997 to 42 in 1998, and 59% of organ donors in 1998 were male.

The number of transplants performed in Canada rose by 40% between 1992 and 1998, with most of the increase coming between 1993 and 1994, when the total jumped by 23%. The number of patients waiting for a transplant has increased by 56% since 1992.

In 1998, 3246 Canadians were awaiting an organ transplant, with patients requiring a new kidney accounting for 80% of that total. Only 4% of those on the waiting list needed a new heart. Of transplants performed in 1998, 61% involved kidneys, 10% hearts.

Canada's organ donation rate of 13.7 per million population is similar to the rates for countries such as Germany, the United Kingdom, Switzerland and Sweden. However, we lag well behind the US, with a rate of 22 per million, and Spain (32 per million). — *Shelley Martin, CMA, martis@cma.ca*

eHealth activity slow, but major growth may be on horizon

It is just a matter of time before rising health care costs force changes in the way medical records are kept, the CEO of a Canadian high-tech company says. "Spending on health care in North America is up to US\$1.5 trillion annually, and [much of] that money is wasted because of duplication and inefficient record sharing," says Claude Haw, CEO of an Ottawa company that wants to merge medical and information technology. Haw, who held senior management posts at Mitel Corporation and Newbridge Networks, says "eHealth activity only amounts to about US\$250 million worth of activity today but is expected to reach US\$3 billion by 2004."

He now heads Mainsource Software Corporation, which developed a program that uses the Web to deliver med-

ical and health care information in different formats to physicians, administrators and patients. It works by "tagging" information about a patient that is held in laboratory and other databases, including text, videos, MRI scans or any other clinical images, so that it is available on desktop computers.

Haw says this and other eHealth developments are not just fancy tracking devices for bean counters: they have the potential to revolutionize health care for patients. "We could move very quickly to a system where patients have their own smart card and can access their own health record through swipe and PIN [personal identification number], just as they can access their financial records at a bank machine," suggests Dr. Christopher Skinner, the

vice-president of product management at Mainsource. Skinner, who has degrees in engineering and medicine and is a clinical neurologist at the Ottawa Hospital, has published and worked extensively in the area of clinical informatics and the impact of informatics on medical education. Just as Canadians are now prepared to pay up to \$30 a month for access to the Internet, speculates Skinner, they may soon have the chance to do the same to gain secure access to their own health records.

Skinner says eHealth innovators all face the same problem: inertia within the health care system. "This system could be adopted almost everywhere immediately [because] the technical architecture is easily applied," he says. "The barriers are political." — *Charlotte Gray, Ottawa*

Public Health

Substance abuse among physicians

Epidemiology

The general perception that rates of substance abuse are higher among physicians than among the general public appears to be based more on folklore than on fact.¹ Prevalence data concerning substance abuse among physicians are generally lacking, and most of the published data are based on descriptive studies that use convenience samples unsuitable for comparison with other populations. The prevalence of alcoholism and illicit drug use among physicians is likely similar to that in the general population,² at about 9%.³ However, physicians may be at increased risk for prescription drug abuse, particularly abuse involving opiates and benzodiazepines.¹

Although physicians probably face no special risk of developing addiction problems, they do confront special problems when they try to enrol in effective treatment programs. Like other professionals such as airline pilots and dentists, addicted doctors pose a risk to the safety of the general public. The medicolegal implications are profound, because the primary mandate of provincial licensing bodies is to protect the public from unqualified or impaired physicians. Admitting to an addiction places a physician's reputation, accreditation and employment in jeopardy. Consequently, addicted physicians find it difficult to seek help.⁴ They suffer a disease of isolation and denial that is often fostered and enabled by silent colleagues; skilful intervention can save lives. Appearance of a problem in the workplace often signifies advanced disease. Too often the diagnosis of an addiction does not emerge until the impaired physician is incapacitated, necessitating urgent removal from work. Physicians should be alert to conditions and behaviours that may signal a substance abuse disorder in a colleague (Table 1).

Most provincial medical associations and addiction treatment facilities provide confidential phone lines that offer guidance to impaired physicians or their colleagues. The Ontario Medical Association receives about 130 of these calls annually; over 30% are from concerned colleagues and about 20% are from the families of impaired physicians.

Clinical management

A comprehensive treatment program for physicians involves: immediate intervention; evaluation and triage at an appropriate facility; uninterrupted therapy, usually in a residential setting; family involvement; and appropriate re-entry into practice with comprehensive case management, monitoring, advocacy and a relapse contingency plan.

The conventional treatment program includes inpatient detoxification, medical and psychiatric evaluation, and rehabilitation with group therapy and attendance at meetings of mutual support groups such as Alcoholics Anonymous, Nar-

Table 1: Identification of the impaired physician

High-risk conditions	Family history of addictions Domestic breakdown Unusual stresses at work
Behaviours	Changes in behaviour from baseline Loss of reliability Frequent medical complaints Self-prescribing of mood-altering medications Mood changes Staff concerns Citations for impaired driving
Signs	Smell of alcohol Ataxic gait Slurred speech Tremor Dishevelled appearance Somnolence

cotics Anonymous and Caduceus (a support group for impaired medical personnel). After full assessment and treatment, the recovering physician is transferred to continuing care, with weekly outpatient sessions continuing for 2 to 3 years. Ideally, a recovery contract is written between the recovering physician and a treating clinician, institution, provincial assistance program or the college.

Relapse prevention

The requirement for close follow-up is believed responsible for the high recovery rates of more than 80%. Factors that can contribute to relapse include unresolved anger, guilt or shame, isolation, failure to focus on abstinence and occupational or legal difficulties.

In general, physicians with substance abuse problems or questions can receive confidential help from addiction resource centres or physician assistance programs operated by provincial medical associations. — *Erica Weir, CMAJ*

CMAJ thanks Dr. Michael Kaufmann for his contribution.

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Research Update

What's bred in the nerves: discovering the gene for a rare neurodegenerative disease

Researchers at McGill University and other institutions have found a genetic mutation that causes autosomal recessive spastic ataxia of Charlevoix-Saguenay (ARSACS), a neurodegenerative disease that is one of many genetic disorders found in a demographically isolated part of northeastern Quebec (*Nat Genet* 2000;24:120-5). The gene involved is the largest uninterrupted length of protein-coding DNA sequence ever discovered in a vertebrate.

The researchers report cloning of the *SACS* gene on chromosome 13q11. The gene consists of a single, gigantic 12 794-bp exon, the scientists said.

ARSACS is an early-onset familial spastic ataxia characterized by prominent myelinated retinal nerve fibres, reduced motor-nerve velocity and absence of sensory-nerve conduction. Of more than 300 identified patients, most are descended from families from Quebec's Charlevoix-Saguenay region. It is estimated that 1 in 22 people in that region are carriers.

Based on the gene sequence discovered, it is possible that the encoded protein could play a role in "protein folding," a phenomenon believed to be involved in the integrity and survival of nerve cells.

"There are no immediate implications [of this discovery] for ARSACS patients," Dr. Thomas Hudson of McGill's Montreal Genome Centre told *CMAJ*. "We hope the next steps, aimed at understanding how the gene causes the disease, will help researchers derive new therapies to control or delay symptoms. But it is premature to envisage gene therapy. Family members of ARSACS patients can have access to a DNA test, to know their carrier status. This may have limited use in the area of prenatal counselling."

The Charlevoix-Saguenay-Lac-Saint-Jean region of Quebec is demographically isolated and is known internationally for its genetic anomalies.

Many of the region's 330 000 inhabitants trace their lineage to European founders who settled there during the 17th and 18th centuries. "Although I can deduce the existence of the ARSACS founders based on our DNA analyses, I don't know who they are," Hudson says.

Other genetic disorders that have been studied in the region include autism, hemochromatosis, oculopharyngeal dystrophy, subacute necrotizing encephalomyelopathy (Leigh's syndrome) and tyrosinemia.

Last year, a paper by investigators at

the University of Quebec's Chicoutimi campus studied inbreeding in the genealogies of 205 patients with autopsy-confirmed Alzheimer's disease (*Genet Epidemiol* 1999;16[4]:412-25). This study found that those with histories of Alzheimer's disease were significantly more inbred than a control group. The Alzheimer's disease was "explained by the high level of inbreeding of a few cases whose parents were related at the first-cousin level." Another 1999 study traced 120 living patients with bipolar disorder in the region, confirming linkages related to chromosome 12q23-q24 (*Am J Med Genet* 1999;88(5):567-87). — *David Helwig*, London, Ont.

Briefly . . .

Worst asthma symptoms caused by prostaglandin D₂

The mechanism behind asthma is under increasing scrutiny. In asthma, environmental antigens trigger immunoglobulin E antibodies, which then activate mast cells. These mast cells release substances that induce inflammation. Experiments with genetically engineered mice now show that one of these inflammation-inducing substances — prostaglandin D₂ — is responsible for the worst symptoms of asthma (*Science* 2000;287:2013-7). When the gene for prostaglandin D₂ receptors was removed from asthmatic mice, they did not experience the hyper-reactive airways typical of asthma. Future therapies targeting prostaglandin D₂ could mitigate asthma's life-threatening complications.

Pathologic protein gives fruit flies Parkinson's disease

Researchers have created fruit flies with Parkinson's disease — one of the few animal models of the disease, and proof that a mutant protein leads to the neural degeneration in the disease (*Nature* 2000;404:394-8). They now hope that the flies will show how the protein works, and provide a testing ground for new therapies. The researchers genetically engineered *Drosophila melanogaster* to express mutated α -synuclein, a protein found in abundance in nerves, whose function is unknown. Two mutations in genes that encode α -synuclein were recently found in families with inherited Parkinson's disease, leading to research into the protein. The fruit flies with mutated proteins have physical signs of Parkinson's disease — progressive loss of dopamine-secreting neurons and intracellular aggregates resembling Lewy bodies — as well as behavioural characteristics. The flies failed a standard vial-climbing test, indicating locomotor defects.

Ottawa MD makes legal history with huge libel award against CBC

Patrick Sullivan

Dr. Frans Leenen thought his professional reputation had been left in tatters when the CBC broadcast a public affairs program on the use of calcium-channel blockers in 1996. Four years later, the CBC knows exactly how he felt.

In a blistering judgement released Apr. 20, Mr. Justice J.D. Cunningham of the Ontario Superior Court found *the fifth estate* guilty of acting with malice against the Ottawa hypertension specialist. He ordered the CBC to pay Leenen \$950 000 in general, aggravated and punitive damages, plus his legal costs. Richard Dearden, one of the Ottawa lawyers who has represented Leenen since his suit was launched in 1996, says those costs will total more than \$1 million.

Leenen now has the dubious distinction of being part of Canadian legal history. "This is the largest [defamation] award against the media in the history of the country," says a jubilant Dearden.

In the end, the hour-long broadcast may cost the CBC up to \$5 million because of the Leenen ruling and an earlier judgement in favour of Toronto cardiologist Martin Myers, who was awarded \$200 000 for defamation last November.¹ The CBC must also pay his costs.

The hour-long TV program dealt with the safety of a calcium-channel blocker, nifedipine. Since there was evidence that its short-acting version posed a risk to patients, there were concerns that the long-acting version, which had been introduced in 1992, might also be dangerous. Leenen, who chaired the Health Protection Branch's ad hoc advisory committee reviewing CCBs, had told the committee "one cannot assume that the long acting [products] are safe" and "it is critical to get outcome studies on the long-acting agents." However, Cunningham said the CBC never portrayed Leenen's views fairly. Instead, it created "the innuendo that Dr. Leenen supported the prescribing of killer drugs."

Cunningham summarized *the fifth estate's* presentation in 2 searing lines. "In order to portray [Leenen] in the role of the 'bad guy' and in order to disparage his views, the CBC took an eminent research scientist, whom they knew to be a

person of high integrity and reputation, and presented him as a devious, dishonest, bumbling fool in order to advance the story line. . . . This was sensational journalism of the worst sort and should serve as an embarrassment to this so-called 'flagship' investigative program."

In an interview at the Ottawa Heart Institute, where he serves as director of the Hypertension Unit — he is also a professor of medicine and pharmacology at the University of Ottawa — Leenen described how the show changed his life. "There was a change in the way colleagues perceived me," he recalls. "It was almost as if there had been a death in the family. And in a way it was very much like there had been a [professional] death."

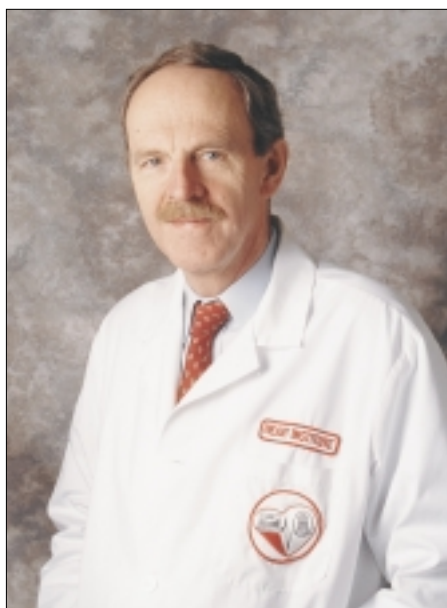
Leenen says a researcher's integrity and independence are his most valuable assets, and the CBC tried to destroy both. "This program," he says, "said I was beholden to the drug companies."

No one involved in producing the show emerges with reputation intact. Cunningham described the group as "parasitic sensationalists." He was particularly vehement about producer Nicholas Regush, accusing him of "self-righteous arrogance" and awarding \$150 000 in damages against him.

He also criticized another defendant, Paul Webster, for being callous about Leenen's financial difficulties.

(Leenen had to remortgage his house to pay his legal bills.) Cunningham said that Webster, whose legal bills were being paid by the CBC, told Leenen "in a callous and insensitive way" that "somebody is going to lose his shirt" and later asked, "How's the mortgage going?" The judge awarded \$50 000 in damages against Webster.

The judge saved some of his harshest criticism for an Ottawa physician, Michelle Brill-Edwards, who was "clearly an unhappy and disgruntled employee of the [Health Protection Branch]. . . . It would not have suited the story's thesis for the producers to inform viewers that Dr. Brill-Edwards was found unqualified for the position of director and that she had lost her case in the Federal Court. I am satisfied that Dr. Brill-Edwards' concerns about the regulatory process and the



Dr. Frans Leenen: "I would have settled for an apology and \$10 000, and the \$10 000 was negotiable."

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.

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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.

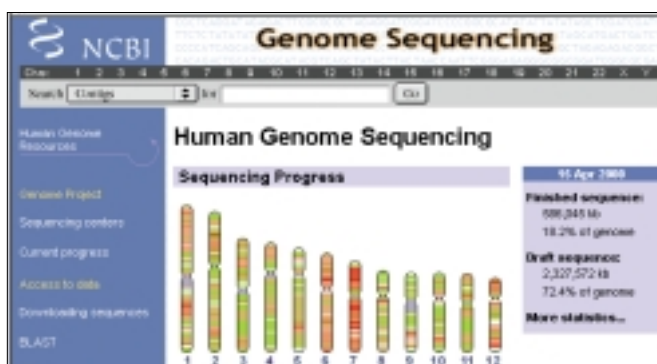
Although they agreed that private-sector involvement is needed to speed product development and that patenting helps encourage research, they are also worried about the misuse of data and about attempts to patent and commercialize genes, thus depriving others of the potential benefits. For example, Celera 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.