

ISSUES & IDEAS

B.C. abandons accepted approval process

Province subsidizes drug that fights age-related macular degeneration despite lack of approval

WANDA HAMILTON

On June 1, the B.C. government began subsidizing two drugs to treat the leading cause of blindness among seniors — age-related macular degeneration (AMD).

Provincial residents with the “wet” form of this debilitating disease saw their costs of Lucentis partly covered by B.C.’s Health Ministry. The second drug that Victoria is now subsidizing is Avastin.

There is a very important difference between these drugs that one million Canadians with some form of the disease must know: Lucentis has been approved by Health Canada as a treatment for AMD. Avastin has not.

We point this out, not because one drug might be superior to the other, but because provincial funding of Avastin calls into serious question Canada’s time-tested system of evidence-based drug regulation, the cornerstone of which is patient safety.

Avastin may turn out to be a good AMD treatment; it may not. The point is, we don’t know yet, because it completely bypassed Canada’s regulatory approval process. Even more troubling is the fact that this happened despite a recent Health Canada warning about inflammation caused by Avastin.

How did non-approved Avastin come to be used to treat AMD?

While Lucentis was still undergoing the rigorous testing for AMD required for Health Canada approval, retina specialists in the U.S. started experimenting and treating patients with Avastin — originally approved as a treatment for colorectal cancer — noting its chemical makeup is somewhat similar to that of Lucentis. This took place in the absence of alternative treatments, since Lucentis had not yet come to market.



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But Lucentis is available now. Meanwhile, the use of Avastin for wet AMD has spread, including in Canada, without the regulatory green light anywhere.

Some doctors have reported patient benefits of Avastin for AMD. But the information is anecdotal only. The lack of extensive clinical evidence about its efficacy and safety caused some doctors and patient advocacy groups to de-

mand a higher level of clinical evidence. As a result, clinical trials have begun in the U.S. and the United Kingdom. But preliminary results are expected only in early 2011. Under our current system of medicine, this clearly means that use of Avastin must be considered as experimental.

Because of the lack of proper safety and efficacy data about Avastin, it has not been approved for use in the eye in

any country in the world, including Canada. Canada has a well-designed and time-tested system of drug review and approval which has served and protected us well, and British Columbia appears to have abandoned this by funding a drug that has not yet been granted approval to treat wet AMD due to insufficient evidence — and when another approved drug is available. Why?

A big part of the issue is money. Lucentis is expensive. It costs roughly \$1,800 per injection; Avastin is cheaper, largely because it has not gone through expensive clinical trials or the approval process to treat AMD. There is also a difference in how it is manufactured and distributed. Pharmacists have reformulated the large batches of the cancer drug into much smaller doses for injection into the eye. By doing so, the cost per injection is much less than for Lucentis, but there is obviously — as the Health Canada warning demonstrates — an increased risk of complications.

It is a difficult situation for everyone — particularly patients. Those with AMD may be confused and uncertain about what to do at a time when they need support and advice most of all. It borders on unethical for B.C. to fund a drug that has neither been reviewed nor authorized for treatment of AMD.

The use of drugs for illnesses for which they did not receive approval (so-called “off-label” use) is a slippery slope. It should be reserved only for situations where there is no viable, approved alternative. That is not the scenario here.

It is a dangerous precedent to bypass the evidence-based drug approval system, one that has been clearly demonstrated to protect Canadians from potential risks associated with unproven medicine. Patients with sight-threatening illnesses deserve better.

Wanda Hamilton is chief executive officer of AMD Alliance International and a former director of CNIB in British Columbia. AMD Alliance International is a global coalition of vision, research and seniors’ organizations dedicated to raising awareness of AMD and the options available for prevention, early detection, treatment, rehabilitation and support services.

Social marketing the key to changing people’s habits

EMMA GILCHRIST

“If only people knew better.” It’s a common refrain among those discussing environmental action — or inaction, as the case may be.

If only people knew how much energy is saved by recycling; if only people knew how much money a programmable thermostat could save them; if only people knew idling isn’t good for their vehicles.

There’s just one problem: Most people do know all of those things and many still don’t change their behaviours.

So, here’s a more illuminating refrain: “If only program planners knew that information isn’t enough to get people to change their behaviour.”

That’s the wisdom of renowned environmental psychologist Doug McKenzie-Mohr, the author of *Fostering Sustainable Behaviour* (New Society, 1999, \$17.95).

Based in Fredericton, N.B., McKenzie-Mohr has been specializing in environmental psychology for more than 20 years. His work has informed programs from Calgary to California to Queensland.

While most “environmental psychologists” focus on the impact of the built environment on humans, McKenzie-Mohr does the reverse.

“It’s very difficult to get from where we are today without us having some idea of behavioural change,” he says.

McKenzie-Mohr works with government agencies and NGOs around the world to develop environmental programs that work. The principles of his community-based social marketing strategies can be applied by nearly anyone, anywhere.

Let’s take programmable thermostats as an example.

Research shows the most common barriers to using a programmable thermostat are getting to the store to buy the thermostat, installing the thermostat, programming the thermostat.

“Telling people they exist and are worthwhile doesn’t address any of these barriers,” McKenzie-Mohr says.

Indeed, community-based social marketing is all about looking at what barriers and motivators exist for any given behaviour.

McKenzie-Mohr cites a project in Australia that has been extremely successful in implementing low-flow shower heads and tap aerators to save water.

Basically, officials went door-to-door to 212,000 households and physically installed the new gadgets — eliminating virtually all of the barriers to change.

“We need to be thinking about delivering programs like that on a massive



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scale,” McKenzie-Mohr says.

Calgary’s Clean Calgary Association is conducting a similar project, called Healthy Homes, albeit on a smaller scale.

Employees are visiting 400 Calgary homes and implementing a host of changes, from compact fluorescent light bulbs to composting to non-toxic

cleaning products, and then conducting follow-up visits a few months later.

“We have really subscribed to [McKenzie-Mohr’s] philosophy,” says Natalie Odd, executive director of the Clean Calgary Association. “Going to one of his workshops is like a rite of passage when you work here.”

McKenzie-Mohr points out that one

major barrier to recycling is the inconvenience of sorting. By introducing a “co-mingled” system, which doesn’t require sorting, a city can thus remove one of the major barriers.

Another significant barrier is knowing what does and doesn’t go into your recycling bin.

“It’s very challenging for someone to remember that long list of items that can go in the container,” he says. “How do you design a program that makes it easy to know what is recyclable?”

What does work is making the rules simple, “so the person just has to know the basics,” he says. A decal on the side of the container showing what can be recycled is also effective.

Next, you can look at motivators, such as charging for the number of bags — “that often quite dramatically increases recycling,” McKenzie-Mohr says.

Banning items from the landfill is another way to go. In Nova Scotia, residents must use clear garbage bags and authorities won’t collect from households with organics in the garbage. This has resulted in a 17-per-cent increase in diversion, McKenzie-Mohr says.

The bottom line? Environmental behavioural change is all about removing barriers and implementing motivators — and basing it all on sound audience research.

Canwest News Service

We need faux memoirs to give us something to live for

ROGER COLLIER

The memoir is one of my favourite literary genres, and I hope to write my own someday, though squeezing a compelling tale from my life won’t be easy.

I was cursed with a happy childhood. I haven’t accomplished anything noteworthy or befriended anyone famous. I haven’t had the good fortune to fall into an addiction to triumphantly overcome, though I did, some years back, kick a three-Snickers-a-week habit. Maybe I can get a chapter or two out of that.

To pad my memoir out to book length, however, will take considerable effort. I could conduct research — visit my hometown, talk to relatives, interview former teachers. I could dig up old letters and photographs and year-books. But whatever I’d learn would only confirm what I already know: My

life story is as boring as rolled oats.

Perhaps a better writer could do more with such meagre material — compose pretty sentence after pretty sentence about riding bikes and shooting hoops, find cosmic significance in every scraped knee, every unrequited crush.

Hey, I enjoy a little hootedoodle on the page as much as the next Nabokov fan. It’s just not in me to write that way. I need something to work with. So I’ll do what many successful memoirists do — make stuff up.

These are trying times for fabulists, I know. Every other month someone’s life story is exposed as fiction. A Jewish girl raised by wolves turns out to be a Catholic girl raised by relatives. A half-Indian foster child who ran drugs in the hood turns out to be an all-white valley girl who attended private school in the burbs. A Holocaust survivor who married a fruit-chucking fake Christian turns out to be a Holocaust survivor who ate imaginary apples.

Unlike them, I won’t get caught. Their mistakes make up my what-not-to-do list. I won’t, for instance, write about drugs. I won’t write about the Holocaust. And, most important, I won’t go anywhere near Oprah. You’d think all faux memoirists would know by now that a visit with Ms. Winfrey is a visit with disaster. That woman could turn the phonebook into fiction.

And so what if it did come out that I wasn’t raised in an Albuquerque mental institution by former cast members of the 1970 off-Broadway production of *Whispers on the Wind*? (This is one of several plot lines I’m considering.) Why do people pretend that honesty is so important?

Society would fall apart if people were always honest with each other. If you told a friend what you really thought about his wife/short game/comb-over, you would soon be short one friend. Lies make relationships possible.

Honesty works sometimes, but peo-

ple expect certain answers to certain questions, and to answer otherwise would be cruel. No mother needs to hear that her baby is ugly. No husband needs to hear that his bedroom skills have slipped from mediocre to poor. No wife needs to hear that her new pants make her bottom look like two hot air balloons trapped in cheap denim.

Sure, many people say that honesty is the best policy, but I don’t understand how anyone could deny that well-intentioned lies are essential to building strong communities. And let’s not forget that many people say “hu-nying gunglin,” which I also don’t understand, nor, I suspect, would anybody else who doesn’t speak Mandarin.

We’re all liars. Why should we expect memoir writers to be different? Should people be held to a higher standard just because they know a metaphor from a simile? The only difference between a fabulist and a person who says your beef-and-banana casserole is delicious

is that one has indigestion.

Faux memoirists could play it safe and market their books as novels, but that would be a disservice to society. Stories of real people who succeed in spite of adversity inspire readers — give them hope that they, too, might one day escape their sad, little lives. They won’t, of course, but the hope is nice.

The problem is that most people are petty, selfish, narcissistic dunderheads who couldn’t inspire a squirrel to eat an acorn. Enter the fabulist. We need writers to fabricate uplifting true stories to fill the inspiration void. It’s philanthropy, really.

I hope my memoir will inspire readers. I hope it will show them that anything is possible. Most of all, I hope my story will make people realize that just because you were raised by heavily medicated singers and dancers doesn’t mean you can’t one day be king of Albania.

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