Northern Light

Louise Binder keeps the activist fires burning. She laughs a lot, too.

October 1, 1999 By Becky Minnich

Louise Binder can pass easily as a soft-spoken, please-and-thank-you Canadian, which is why it's difficult at first to imagine her getting 86'd from a hotel by the Royal Canadian Mounted Police while loudly lambasting a prime-minister candidate for his AIDS policy—a stunt that landed her in the pages of POZ in October 1997. In fact, the politely veneered Binder is a tough-as-nails organizer who has made an international name for herself since testing positive in 1993. A former labor lawyer, Binder currently cochairs the Canadian Treatment Advocates Council, an organization of north-of-the-border PWAs, which will cohost the first-ever Canadian conference on women and HIV next spring. When Binder spoke with POZ from her Toronto home, which she shares with her male partner of seven years, she was busily packing for a trip to the Stratford [Ontario] Theatre Festival to see Shakespeare's The Tempest.

What's life been like over the past two years?
Very busy. We've been trying to improve the drug-review process in Canada, analyzing the problems with it, why it's so slow, how to speed it up. The issue of drug pricing is very pressing as well. Just last week we had a demon-stra-tion and press conference about lowering the price of Sustiva.
Are AIDS drugs cheaper in Canada than in the United States?

Not by much. Here we have a national board that sets drug prices based on the median rate among the G-7 countries. And, in fact, it's the U.S. prices that really drive up the market in Canada and everywhere else.

Many Americans envy Canadians for their universal health care system.

And you should, but I have to say it's definitely not perfect. Besides federal funding, each province has its own health care budget and subsidizes health care, including the cost of AIDS drugs, but it's based on available revenue. So, the poorer provinces don't put as many drugs on the approval list for payment, which is a problem.

Are you taking any of these drugs?
I've been on Crixivan [indinavir], d4T and 3TC for about three years now, and the combination

seems to be working. I haven't been sick at all. My bloodwork numbers are good, and I have an undetectable viral load.

But I've had a lot of side effects with these drugs. Some of them come and go, like hair loss. My hair got very thin about a year and a half ago, but it's starting to grow back. I have a buffalo hump from the Crixivan, which goes away and comes back. The lipodystrophy has made my legs extremely thin, while my breasts have enlarged incredibly, and I have no waist to speak of. Also my face has gotten very puffy along the jaw line, which looks odd because I've always had a thin face. I also have chronic gastrointestinal difficulties, which nothing seems to help, some peripheral neuropathy and elevated triglycerides, which I'm told is also a side effect from the drug combination.

What health measures are you taking to cope with these problems?
I keep an eye on sugars and almost never drink alcohol. I attempt to exercise, although I'm not a real "exercise" person. I eat a lot of fruit and vegetables, and try hard to eat fresh food. I'm very careful about washing food, although my friends sometimes laugh at me about it. I try to get enough sleep every night, usually about nine hours, and reduce my stress level by doing things that I enjoy, like spending time with friends, laughing. Our lives are so serious so much of the time, and I find it really helps to keep a sense of humor.

What are your long-term goals?
I don't set goals very far in advance. I'm one of those people who hasn't accepted that I'm going to live that long. I'm kind of a pessimist. I know people who, as soon as their numbers got better, they stopped thinking about death and proceeded to live a perfectly normal life, but I never got to that place. I tend to live, instead, from milestone to milestone. I just had my 50th birthday—I never imagined that I would live this long, so that was a real celebration. Now I suppose my next milestone is the millennium—another thing I never thought I'd live to see.

How do you see your future as an activist?
I'll continue to do the work as long as the issues are out there. My activism helps my health. I strongly believe that whatever it is, it's important to pursue work that has meaning to you. For some people, it may be painting pictures, for others it may be writing a book. For me, because I'm not really creative, doing this work is what gives my life a day-to-day sense of meaning.

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