

## **When Tea and Sympathy are not Enough: The Catastrophic Gap in Prescription Drug Coverage in Atlantic Canada**

### **10:45 Panel – Covering Atlantic Canada: Regional Dimension of Catastrophic Drug Coverage**



This is the transcript of remarks made by **Linda Wilhem** during the second panel of the AIMS “When Tea and Sympathy are not Enough” conference.

*Linda Wilhelm was diagnosed with Rheumatoid Arthritis in 1983, at the age of 23 with 2 babies and no time to be sick. In 1999, after a year in a wheelchair and fighting for access to Enbrel, she decided that she had to do what she could to help improve the quality of care for people with arthritis. Linda began meeting with politicians and since then has been working constantly with the Arthritis Society, first in New Brunswick, and then with the Canadian Arthritis Patient Alliance. It has been six years since gaining access to the medication that transformed her life. She now walks three kilometres, three times a week.*

#### **Linda Wilhelm:**

I'm going to try to bring this back to how this affects people on a personal level, and I'll start a little bit about how it affected me.

I'm on Enbrel, and I've been on it for six years. I had one year of my life taken away from me because of a lack of access to a catastrophic drug, and that's what motivates me to try and continue to change and improve things for others. Now I work almost solely on access to medications issues, and getting the patients' voices heard by decisions makers, and by anybody who is willing to listen.

Patients in Atlantic Canada are being harmed by the government not addressing the catastrophic drug issues, and I think we all know that. We know there is no program in place to help those facing high drug costs, and I hear from these people on a weekly basis. They get my name through letters I've written to papers, through doing public forums like this, and I get calls and e-mails from people just asking where they can turn to. And I'll tell you, it is heartbreaking when you try to help people and you can only do things in a piecemeal way for them.

In New Brunswick patients have to apply for a card, through Family and Community Services, if they're not under income assistance. Many of these people are working full time, but don't have insurance. They feel that going to Family Community and Services makes them somehow applying for income assistance. There's a stigma attached to that, and many are reluctant to do it. So it is only logical that many people don't apply for assistance, and without the medication people are more likely to become disabled and use the health care system. They may eventually end up on income assistance, the thing they tried to avoid in the first place.

Applying for financial assistance in New Brunswick puts your whole life under a microscope. It requires extensive paperwork by physicians, who really don't have the

time to complete all the paperwork. So I spend a lot of my time calling doctors, e-mailing doctors, to say, "Please send this paperwork. This person is suffering and needs the medication and can't even begin the process until they've applied." Many don't know they're eligible, or don't know there's a program to help them. When I tell people to apply through Family Community Services first, they don't know where to begin. They don't know how to negotiate through the bureaucratic system. You know, in some ways I'm a professional patient. I even get told that I'm not a typical patient, because I've managed to learn and negotiate the system since I began this process in 1983.

And so here I stand, 26 years later, and yeah, I've learned the system, but it has taken a lot of work, and now I try and help others. But there's many people that don't know about me, or I don't hear about them, and I know they're slipping through the cracks and suffering.

This is a case study of a couple I recently worked with. They are from New Brunswick- a 65-year-old man who had just retired, and his spouse who has rheumatoid arthritis. Her arthritis was very well controlled by Enbrel, before her husband's retirement. Her husband's company only insures the former employee, not their spouse, after retirement. Purchasing private insurance was not an option. People with rheumatoid arthritis can't buy private insurance. They'd just laugh you right out of the office. She's 57, and doesn't yet qualify for any senior's plan.

So the wife now has to go to Family Community Services, and she has a \$30,000 RRSP. These people don't own a home. This \$30,000 is their only cushion for their retirement. He has his retirement pension that's for their daily expenses. This money is ... imagine, if you need a car five years down the road or major home renovation or any kind of expense. This was their only savings. The worker from Family Community Services told her not to even think about trying to hide that \$30,000. She would have to use it up before she can qualify to get any assistance through Family Community Services. And if she tries to hide it, they will find out. Imagine the empathy that's there, that people are facing. This happens, and has happened on more than one occasion to people I've talked to. Without her medication, the probability of this woman requiring excessive medical intervention, being hospitalized, and losing her independence is close to 100%.



As I said, I lost a year of my life because I didn't get a medication. I went through every medication that there was for rheumatoid arthritis at the time. Now I'm doing well, but without this medication I would be right back where I was then. And at the time when I decided that I wasn't going to tolerate it anymore, in 1999, after a year in a wheelchair, I ended up in the hospital in Fredericton. I was there for two and a half months. They tried to switch me and tried to discharge me. I had three children at home, but I couldn't go home because I couldn't take care of them. I couldn't function any more. I said that was enough; I wasn't going home until they could find something that was going to help me. Eventually, because I had two very wonderful doctors, who kept switching me from orthopedics to rheumatology for about two months, the government

decided to give me the medication, and I was able to walk out of the hospital within two weeks. Where is the cost savings to government to deny these medications?

The ten year cost for my treatment of RA, and we did this as a case study on me, when I was trying to get access to the drug, was \$576,826. The ten year cost of Enbrel was approximately \$150,000. In Atlantic Canada, right now, many people with inflammatory arthritis are not receiving appropriate medications. I lead arthritis self-management programs, and in almost every class I take, there's somebody that should be prescribed a biologic, but physicians are reluctant to even prescribe them because they know the battle that the patient will go through to get access to them. The cost to the health care system and to society is enormous.

In 2006/2007, the New Brunswick government is going to spend \$2.5-billion on health and senior care. And despite the complaints about the rising costs, they have to bear some of the responsibilities for some of them. I see some of the changes that are being made and I applaud them, but why weren't they made ten years ago? Why are changes so long in coming, and only when things come to a crunch? Even though the warning signs were obvious, there's been no adequate preparation for the baby boom generation.



Panelists listen to Linda Wilhelm, the final speaker of the morning at AIMS' When Tea and Sympathy are not Enough conference. Left to right: Brian Lee Crowley, John Abbot, and Rob Weld.

Governments need to stop talking and actually create a patient centered health-care system. They have to remove the silos, both in budgeting and in the health care setting itself, where you have to go see your family doctor, and then you have to go see the physiotherapist, and then you have to go see the orthopedic surgeon, and then you have to go see the community social worker. These things are happening at a slow pace in a community health care setting, which is a perfect setting for treatment of arthritis patients.

It used to be, 20 years ago, arthritis patients spent about a month out of every year in the hospital. That's what I did, and most of the people I know did, because they couldn't manage their disease anymore and there was nothing more that could be done, so they put you in a hospital bed to rest, inject a few joints, and do some physiotherapy, and then sent you on your way. There's very few, if any, hospital beds for arthritis patients anymore because the care is supposed to be supplied in the community. The breakthrough drugs have been the reason for that. There are no more beds needed, and believe me, most people don't want to be in the hospital. They'd rather receive the care in the community, and it is cheaper to receive it in the

community, but there's no acknowledgment in the budgets of that.

Common sense tells us that moving away from hospital-based models of care, we need better health interventions in the community. Access to new medications is one of those interventions.

Governments in Atlantic Canada have excluded patients from the table in discussions on health policy development and implementation. This is happening in other areas, but not in Atlantic Canada. Without input from all stake holders, health promotion and disease prevention strategies, will not be successful. If you don't include the patients in the process and in the changes, there's no way you are going to succeed. It's what we've seen for the last 40 years. You've got to bring patients to the table to try to figure it out. I was at a conference recently, where they were talking about patient education models, and developing a new patient education model for somebody with arthritis. They wanted to get all the doctors in the room to develop it, but they weren't going to bring any patients into the room. Again, that would be the reason why it wouldn't work. Like the other education, it hasn't been as successful as it could be, is because they're not using patients when they develop it.

British Columbia has patient representation on working groups, developing their chronic disease management strategy. Health Canada included patients' representation on their expert advisory panel that reviewed the Cox 2- I was one of those patients. Health Canada has invited patients or consultations on national pharmaceutical strategy, strengthening real world safety and effectiveness in the ones that are ongoing right now. Patient representations were included in the Canada's consultation on that, ensuring a safe and adequate drug supply and defining the patient/practitioner relationship. These things are all happening across the country, but not in Atlantic Canada.

The Ontario drug benefit, you've heard about 102, we don't know how that is going to roll out, but there are patient groups that are watching and making sure that the things that we want are implemented. There is also the recent announcement of the Ontario self-management network, which is including patients in the planning and execution.

We need a voice for patients on Pharmacare policy. They have to be included at the table if it is going to work and going to address the needs that actually are there.

Then I will just try to finish with this slide, because it really speaks to me, is that never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is really the only thing that ever has. (Applause)