TITLE: BAD BLOOD

PRINCIPAL SPEAKERS: Anna Marie Tremonti, CBC Host of “The Current”
                   Michael Tymchuk, CBC Reporter

(Anna Marie Tremonti)
And a Vancouver Island First Nation vows it will never let a scientist take advantage of it’s
people again. This particular incident has become a textbook case here and abroad about the
ethics of medical research in indigenous communities, both for scientists and native peoples.
And it’s brought the question of who owns a person’s blood to the forefront of the ethical debate.

We’re going to talk about bio piracy later in the program. But for the Nuu-chah-nulth, the
blood’s return could also foster fresh research into ailments plaguing the community, particularly
arthritis.

Four years ago CBC reporter Michael Tymchuk was one of the journalists who first broke the
story of what happened to the blood, and now he has prepared a documentary about the blood’s

(Michael Tymchuk)
Good morning.

(Anna Marie Tremonti)
The whole idea in the beginning was to investigate the high rates of arthritis in this community,
wasn’t it?

(Michael Tymchuk)
Absolutely. And they do have not only high rates, they have unusual forms of arthritis and they
have unusual clusterings of it within families and between families. It’s quite bizarre and that’s
why quite a long ago in fact, local doctors and specialists who had been treating them as patients
for arthritis, decided that there was something they had to do about it.

Now this is not run of the mill arthritis we’re talking about, sometimes one person would have
more than one type. And sometimes individuals in the same family would have different types.
And when we talk about the numbers, some forms of arthritis that they suffer, three hundred
times the occurrence rate that you would find in other population groups.

(Anna Marie Tremonti)
Three hundred times.

(Michael Tymchuk)
Yes.
(Anna Marie Tremonti)
Wow.

(Michael Tymchuk)
Including weather dependent severe pain without swelling, and again a lot of the cases of arthritis were running in a particular family or families.

(Anna Marie Tremonti)
But the blood ended up being used for something else other than genetic research.

(Michael Tymchuk)
Yes. They signed consent forms specifically for arthritis, but the researcher after doing basically just a very short research project on the blood, he moved away, he took the blood with him and he began using it for other kinds of research, usually anthropology related stuff, very interesting work actually in the field of anthropology, but had nothing to do with what the First Nations had actually signed for and they still had a real problem with arthritis. And so they felt not only betrayed, they also felt like gosh, this is not doing us any good. And so this guy left, he never told them what he was doing, never asked for permission. He just basically disappeared off the scene for, as far as they were concerned. They’ve now taken steps to ensure that they’re in control of any researcher who comes on their territory, including whether they can use the blood that’s been returned or not.

(Anna Marie Tremonti)
Okay, Michael Tymchuk, lets listen to your documentary.

(Playing of documentary)

Michael Tymchuk
Tell me what’s over there.

(Female)
So that’s nine boxes of documents. And so...

(Michael Tymchuk)
Dr. Laura Arbour is walking me over to a stack of tattered brown cardboard boxes sitting in an office in a downtown hospital in Vancouver. The boxes contain paperwork, documentation for the several hundred samples of blood returned from Oxford University to the Nuu-chah-nulth people.

The blood itself, serum actually, sits in a medical freezer 20 minutes away at the University of British Columbia.

Dr. Arbour is among a small group of scientists trusted by the Nuu-chah-nulth to look after the blood and documentation until the First Nation decides what should happen to it.

Now there is a certain twisted irony to the moving company boxes the blood and documentation
arrived in. The company logo features a big red stylized head of an Indian chief with the words Red Man and Mayflower emblazoned on the side. Intentional or not, it’s a further insult in this story of betrayed trust that began 20 years ago on the west coast of Vancouver Island.

(sounds of children playing)
These kids are playing on the docks of the Ahousaht reserve just north of Tofino and Clayoquot Sound. Nuu-chah-nulth children full of life, bouncing around like youngsters everywhere, oblivious to the possibility their young bodies may already harbour the seeds of a crippling disease.

The Nuu-chah-nulth are at high risk for developing arthritis, especially unusual forms in odd combinations often in family clusters. Former Nuu-chah-nulth chief Larry Baird knows the disease firsthand.

(Larry Baird)
Oh yes, it’s been, my mom, she was, had the classic symptoms of the swollen knuckles and all the joints and everything like that. And my sister is going that way. But I do know some people that are, that are in wheelchairs, they’re in wheelchairs. So yes, it’s, there’s quite a number up and down the coast.

(Michael Tymchuk)
How bad does it get with you?

(Larry Baird)
Well there are times where I got to take my watch off, I got to take all my jewellery off, rings especially where I can’t close my hand and they swell. And then all the knuckles are just aching and the arm is aching and if spend a day in pain, I’m usually fatigued the next day. You’re just fatigued from the pain you’re in, so yes, it hurts. It hurts like the dickens.

(Michael Tymchuk)
Because of the high rate of arthritis in some families, in the 1980's local doctors began to suspect heredity as a cause, so they contacted Dr. Richard Ward to look for a genetic link. At the time, Ward was a geneticist at the University of British Columbia.

Ward needed blood to do his research. And under the auspices of the university and the federal government, Ward became a fixture in Nuu-chah-nulth communities, setting up clinics and collecting more than 800 samples, one of the largest ever collections of native blood in Canada. Larry Baird remembers signing a consent form for him and his family and giving blood.

(Larry Baird)
I knew at some stage in my life I was going to have arthritis. And I saw the condition my dad was in, I saw the condition that my mom was in and I knew that I was going to be subject to the same pain and I wanted, and through this research with Ward, I was, I was hopeful, very, very hopeful that holy cow, and not only for myself, but for all Nuu-chah-nulth, my sister and aunts and all them. And other people, my friends that have arthritis. So I was hopeful that this was going to lead somewhere.
But it didn’t lead anywhere. In the late 1980's, Ward co-authored an article about arthritis among the Nuu-chah-nulth in the Journal of Rheumatology. In six and a half pages of medical language and charts, genetics only got an inconclusive two sentence reference. But Ward and the blood had already left Canada by the time that article was published.

He had moved on to the University of Utah, using the blood to determine the age and origins of the Nuu-chah-nulth people, a field known as biological anthropology. Numerous anthropology articles followed, all citing genetic research on the Nuu-chah-nulth blood, and there’s no record of any further arthritis research.

Ward’s stature grew and he soon became head of the Institute of Biological Anthropology at Oxford University. And the blood followed him to England. None of this was known to the Nuu-chah-nulth.

Larry Baird only found out about Ward’s work after one of his anthropology papers happened to attract some local media attention.

Right off the bat my first reaction was that I had given blood under false pretenses. And that I had been duped by this Ward character. And then no, no, no, no, this is not right, you don’t give something to somebody and they promise to give you reports and the blood was used for something it wasn’t intended to be used for. That incensed me that somebody would dupe me and nine hundred other people and use our blood for other things.

After months of stonewalling, Ward grudgingly conceded he had not asked permission to do any further research with the blood. He also excused what he did by saying that what had happened was at the time, fairly common practice among many researchers.

And it wasn’t until the story became well known internationally that Ward openly acknowledged he had made a mistake.

Anything that I can do to help achieve some kind of reconciliation I’d be more than happy to do. I mean the responsibility for the situation is clearly mine. And if there’s an opportunity to both apologize and to explain to people what happened, I’d be more than happy to do that.

But Ward never did return the blood or make an apology. And it wasn’t until after he died unexpectedly in 2003 that some Canadian scientists sympathetic to the Nuu-chah-nulth, secured the blood from Oxford. Dr. Laura Arbour was among them. For the geneticist, getting the blood back was simply the right thing to do.

We heard from the people from some Nuu-chah-nulth members that they were very concerned
and very upset that the research that they had consented was not carried out. I heard over and over again that they still had pain, they still wanted research done. They were still, I suppose they felt exploited that they did not have the research that had been promised, carried out.

I’m not even sure that they were as concerned about the type of research that eventually was done, that had had nothing to do with health. What I heard over and over again that they were upset that the research they wanted done and consented to was never done.

(Michael Tymchuk)
With the return of the blood, using it for new research into arthritis is a possibility. But this time the Nuu-chah-nulth will call the shots. The tribal council has set up its own research ethics committee. Larry Baird is chair of the group. The committee is responsible for vetting and supervising all new research projects involving Nuu-chah-nulth people.

But for Baird, keeping the door open to researchers has not been an easy decision. Many indigenous peoples around the world accuse scientists of bio piracy, seeking fame and fortune at native people’s expense. Baird sympathizes with that point of view, but sees the potential for greater good in allowing more scientific research.

(Larry Baird)
There was a time where I, yes, I thought we were being ripped off, that we were going to close the door on everything until you kind of take a deep breath and you go well what’s that going to prove. You know cause I still, I still want answers, and I’m hoping we can get some answers in my lifetime about arthritis for myself and for the Nuu-chah-nulth.

But I went down that road, I read all the, all the material there is on bio piracy and all that. And I guess when you get a little older you start to look through different lenses and different eyes and you go well, how is that, I got nothing against scientists, it’s just we need help. But we need outside help that we can trust, that we can work together in a cooperative spirit, because if we’re taken advantage of, we can close the door pretty quick.

(Michael Tymchuk)
Dr. Laura Arbour is an adviser to the research ethics committee. As a geneticist, she’s heard the criticism of her trade before and considers some of it valid. But with the danger of doors closing, she’s eager to help the Nuu-chah-nulth and other scientists keep this door open for the benefit of everyone.

(Laura Arbour)
I do believe that research is important. I believe that health research is important. That genetics is part of the bio medical aspect of research. And that if it’s going to be done, it has to be done well.

(Michael Tymchuk)
But there is one door Larry Baird is determined to keep closed at least for now. He says the Nuu-chah-nulth are owed an apology, especially from Oxford where Ward and the blood stayed for almost a decade. Baird says to date, Oxford has only issued a press release acknowledging the
return of the blood and expressing the wish for good relations with the Nuu-chah-nulth people.

And he’s got a few choice words in mind for any researcher who comes knocking with an Oxford business card in hand.

(Larry Baird)
Go to hell. We have not concluded this issue. It’s not concluded just because they say it’s concluded. The fellow died, that’s why we got the blood back. I think what it is it’s just those, those Indians from the west coast and they may have not have said it, but their actions speak volumes. They owe us.

(Michael Tymchuk)
And if the Nuu-chah-nulth get their apology from Oxford it will be a victory. But not necessarily one that will make life easier for these Nuu-chah-nulth children as they grow up. The only victory that really counts will come if the blood can be used for what it was originally intended, for research to find some relief from the arthritis plaguing these people, a scourge often handed down from parent to child.

(End of documentary)

(Anna Marie Tremonti)
We’ve been listening to a documentary by the CBC’s Michael Tymchuk in Victoria. Well we’ve been hearing about a fight to keep the blood of a community in the community. And in the last half hour we’re going to explore the issue of bio piracy and Canadian attempts to keep researchers working within ethical guidelines. That’s coming up in our last half hour. I’m Anna Maria Tremonti, and this is The Current on CBC Radio One.