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Nuu-chah-nulth blood returns to west coast

By *David Wiwchar*
Ha-Shilth-Sa Reporter

Ahousaht - After a 20-year journey halfway around the world, hundreds of vials of Nuu-chah-nulth blood have returned home to the west coast. And although people welcome its return, many remain critical of the system that allowed its misuse in the first place.

After a 20-year journey halfway around the world, hundreds of vials of Nuu-chah-nulth blood have returned home to the west coast. And although many people welcome its return, many remain critical of the system that allowed its misuse in the first place.

Dr. Richard (Ryk) Ward took 883 vials of blood between 1982 and 1985 under the guise of a $330,000 Health Canada funded study of arthritis amongst Nuu-chah-nulth; then the largest-ever genetic study of a First Nations population in Canada.

Since there are multiple forms of rheumatic disease in a high proportion of Nuu-chah-nulth, particularly Ahousaht, Ward thought he could show a genetic predisposition and then begin working towards a cure.

"We feel that if a proper study is carried out it will identify all people who have a problem with their joints, and a physiotherapy treatment can be started as a way of helping them," Ward wrote in a 1981 letter to the Nuu-chah-nulth Tribal Council. "In order to carry out the study, I would like to survey every person in Ahousaht so that we can be sure exactly who has a problem with rheumatic disease and who heeds help."

According to Ward's final report, published in 1987, his team of researchers interviewed 1,878 (82%) of all 2,300 adult Nuu-chah-nulth, in 13 different reserve communities and members living away from home in Port Alberni, Tofino, Nanaimo, and Victoria. Of those surveyed, 883 people (44.3%) were selected to give 30 ml of blood so research could begin on whether there was a genetically inherited aspect to rheumatic diseases.

"In Caucasian populations the overall prevalence is of the order of 1%," Ward described in his project overview. "The prevalence rates for rheumatoid arthritis in adult Native Indians are between 3% and 8%," he wrote.

But after he failed to find any genetic markers in the DNA, he shelved the study, and that's where things started to go wrong.

In 1986, Ward left his position as Associate Professor of Medical Genetics at the University of British Columbia. He accepted a position as Associate Professor of Human Genetics at the University of Utah, where the U.S. Department of Health offered a further $172,000 to allow further study of the blood. Again, he found nothing. In 1996, he accepted a position as the head of the newly-formed Institute of Biological Anthropology at Oxford University in England, where he used the blood himself, and loaned it to other researchers for a variety of studies.

These Nuu-chah-nulth blood samples were used to produce hundreds of academic papers were produced on topics as diverse as HIV/AIDS and population genetics.

In January of this year, nine boxes of documents, and hundreds of vials of Nuu-chah-nulth blood serum arrived at the University of British Columbia. The blood was placed into a freezer at UBC, and the documents were taken to the BC Children's Hospital in Vancouver, where they sit in a corner of Department Head Rob McMaster's office.

"Our family has been hit pretty hard by arthritis," said Ahousaht Elder Cosmos Frank. "It's really, really hard to watch someone you love suffer like that when you can't do anything to help. It's hell".

"He profited at our expense," said Larry Baird, who offered his blood, and the blood of his children, for what he saw as a 'very important study'.

"We were of the understanding that we would have the results of the study within a year, but he never told us anything after. He disappeared," said Baird. "He published more than 200 papers and became the top guru in his field because he was carrying our blood around with him. He used us like cheap guinea pigs, and that incenses me."

EFFECTS OF ARTHRITIS:

People living with rheumatic diseases such as arthritis will do just about anything to ease the suffering.

"Having arthritis pain is like a constant toothache. You can't get at it or do anything about it. It just robs you of your power and energy," said Baird, who suffers the debilitating effects of the disease as his late mother did, and as his daughter is now beginning to experience.

Ahousaht Elder Cosmos Frank cares for his wife of 55 years, crippled with the same form of arthritis that took the life of his eldest son.

"Our family has been hit pretty hard by arthritis. My wife Katherine, and four of our daughters all have it. Some days my wife can't even walk. It's really, really hard to watch someone you love suffer like that when you can't do anything to help ease their agony," he said, coming close to tears. "It's hell."

In 1999, their eldest son died of pneumonia at 47 years of age. Frank believes his son succumbed to the respiratory condition because he was weakened from a ten-year battle with a crippling form of arthritis.

"We were of the understanding that we would have the results of the study within a year, but he never told us anything. He disappeared," said Larry Baird. "He used us like cheap guinea pigs, and that incenses me."

There is no cure for any of the many forms of rheumatism and arthritis that affect the Nuu-chah-nulth, and according to Larry Baird, many people spend hundreds of dollars each month on pain relief medications, which exacerbates an already difficult situation for those who are impoverished or unemployed because of the debilitating effects of the disease.

FRAUD:

Ward's consent form made it clear that the study was about rheumatic disease. But at the same time he was drawing blood samples in Ahousaht, he was interviewed by a BBC television crew for a documentary called *In Search of the First Americans*, and he said he was tracing the evolutionary history of First Nations by studying their DNA.

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Blood returns

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"I remember them coming around with a whole team, and they took blood from all my eight children. It was in the summertime, and they took the blood right on our porch," said Gertrude Frank. "They told us they were going to find out why so many of us have arthritis. I was interested because my mother had arthritis, I have arthritis really bad, and some of my children have it, including my oldest daughter who has it really bad now," she said.

"He knew exactly what he was doing and he should have been professional enough to tell us what he was going to do with our blood," said Edwin Frank. "To have a professional person do that kind of thing to me is a shock," he said.

"If he knew what he was going to do with the blood, he should have been upfront with us," said Edwin and Gertrude's daughter Noreen John, who was 22 when her blood was taken.

"It was only supposed to be used for arthritis research and to help others," said Marla Jack. "Just because we're First Nations doesn't mean you can do whatever you want with us."

"I remember it happened in the summer, because I got called up from swimming to go to the clinic," said Marla Jack, who was 13 when she was volunteered to participate in the study. "It was only supposed to be used for arthritis research and to help others. The blood is technically still mine, so I don't see how they can do anything other than that without my permission," she said. "Just because we're First Nations doesn't mean you can do whatever you want with us."

BIOLOGICAL ANTHROPOLOGY RESEARCH:

Through analyzing the genetic sequences of the Nuu-chah-nulth blood, Ward released a 1991 paper announcing the Nuu-chah-nulth had been a distinct genetic group or "lineage cluster" for between 41,000 and 78,000 years. This calls the Beringia Land Bridge theory into question, as many anthropologists believe First Nations people came from Asia via a land bridge to Alaska 15,000 to 33,000 years ago. Ward concluded the genetic diversity existed prior to the assumed period of migration to the Americas. Ironically, the article concludes by thanking the Nuu-chah-nulth for their "collaboration".

HOW THE BLOOD GOT HERE:

When the original story about the Nuu-chah-nulth blood broke in September 2000, academics across Canada and the United States were furious.

"It's a major case and a startling example of how we don't do a very good job of training our scientists about the basics of research ethics, " said Dr. Michael McDonald, Chair of the Centre for Applied Ethics at the University of British Columbia. "It has been very important that the Nuu-chah-nulth have shared their knowledge and their experience with the rest of the world, so we can all make sure this doesn't happen in Aboriginal communities ever again," he said.

Numerous international meetings sponsored by Health Canada, Canadian Institute of Health Research, National Council on Ethics in Human Research, and United Nations Educational, Scientific and Cultural Organization focussed on 'the case of the Nuu-chah-nulth blood', to discuss what went wrong and how to prevent similar situations in the future.

Around the same time, the Institute for Aboriginal People's Health was launched, and the case became a priority for the new organization. "This case was part of a larger move that was going to treat Aboriginal people with respect," said University of British Columbia clinical geneticist Dr. Laura Arbour, who took an interest in the case when she first heard of it in 1999. "It's not uncommon for related secondary research to happen, but what made this case unique was the secondary research was completely unrelated to health as it was about lineages," she said.

In an interview with *Ha-Shilth-Sa*, Dr. Ward said he would "do basically anything that's feasible to set matters to right", including sending the blood and associated data to another repository.

On February 14th, 2003, after bicycling home from his Oxford office, Dr. Ryk Ward suffered a heart attack and died near the steps of his home.

The next day, Arbour received a phone call from a colleague at McGill University in Montreal, concerned that the blood could become the property of Oxford, where it would be overly protected or destroyed. He advised her that the time was right to try and bring the blood back to the west coast.

Arbour contacted Simon Read, Director of Nuu-chah-nulth Community and Human Services department. Read then contacted Oxford's Laura Peers, and many other people became involved, working to bring resolution to this case of research gone wrong.

Ward's widow Maria Ramirez, believed to be Mexica (Indigenous Mexican), was "anxious that the blood samples be returned, and is sorting through his papers to locate all the records pertaining to the blood samples," Peers wrote in an e-mail to Read.

"It has been very important that the Nuu-chah-nulth have shared their knowledge and their experience with the rest of the world, so we can all make sure this doesn't happen in Aboriginal communities ever again," said UBC's Dr. Michael McDonald.

In January of this year, nine boxes of documents, and hundreds of vials of Nuu-chah-nulth blood serum arrived at the University of British Columbia via medical courier. The blood was immediately placed into a freezer at UBC, and the documents were taken to the BC Children's Hospital in Vancouver, where they sit in a corner of Department Head Rob McMaster's office.

RESEARCH ETHICS COMMITTEE:

At the July 11th, 2003 Nuu-chah-nulth Tribal Council meeting in Port Alberni, Chiefs and delegates voted in favour of the formation of a Nuu-chah-nulth Research Ethics Committee. The committee would be responsible for reviewing all research proposals involving Nuu-chah-nulth subjects, and would arrange the return of the blood samples from the Institute of Biological Anthropology at Oxford.

The committee currently consists of: Larry Baird (Chair), Helen Dick, Matthew Lucas, Karla Point, and Darleen Watts.

"People kind of forgot about the blood study and I was the only one asking questions," said Baird. "It bugged me

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Ahousaht doctor works under legacy of research

By *David Wiwchar*
Ha-Shilth-Sa Reporter

Dr. John Armstrong and his assistant Iris Frank in Ahousaht Medical Clinic.

Ahousaht - Dr. John Armstrong has been the primary family physician in the remote community of Ahousaht for the past 18 years. Throughout the time of his practice, Armstrong has faced numerous questions from arthritis sufferers on whatever happened to their blood.

"Many people have asked me what became of the study, and I've had to tell them that I've never heard of any answer, just a description of the problem, and that doesn't really help people much, just to know that they have arthritis. They already know their life is severely impacted by this disease, and people want answers, not necessarily for themselves, but for the grandchildren," said Armstrong. "That's the thing I see now amongst the Elders, is people want research to be done so their children and grandchildren don't develop arthritis," he said.

"Many people have asked me what became of the study, and I've had to tell them that I've never heard of any answer, just a description of the problem, and that doesn't really help people much," said Armstrong.

"There are a large number of Nuu-chah-nulth people affected by various forms of arthritis, that are classified as an auto immune type of arthritis, as opposed to a wear and tear type of arthritis caused by joint damage or injuries. These are diseases where the immune system is attacking the joints, and we see predominance in certain families," said Armstrong. "I believe there's pretty overwhelming evidence that there is at least a tendency for some forms of arthritis to occur in certain families. Sometimes you'll see with one family, one child has rheumatoid arthritis, and their brother or sister has Lupus. That to me is quite interesting, that you sometimes see a mix of different forms of arthritis in the same family that we think of as being entirely different diseases," he said.

"So having this kind of direct observation put together with genetic studies and other kinds of laboratory investigations that are now available could really lead to some exciting developments in terms of early identification of people with arthritis and early interventions in terms of what's available for arthritis, and perhaps down the road prevention strategies that will help certain people from developing arthritis who are most at risk," said Armstrong, adding the need for research towards a cure continues.

"There's been a gap in research over the past 20 years since that original study. The samples weren't available for quite a while, and now that they are I hope further work will be done. Perhaps the genetic methods weren't as advanced as they are now. There are many more people who have developed arthritis since the study was done, many of whom were originally affected and identified in the study," said Armstrong. "Given the profile of this report, hopefully some researchers will offer some assistance. I'm not sure of the state of the data that was collected 20 years ago, or the condition of the blood samples, but certainly there's an opportunity for people to take more blood samples for research that will be of benefit," he said, adding the development of a Nuu-chah-nulth Research Ethics Committee is a great step forward.

"There's no reason why future research couldn't be done under the guidance of a well formed ethical committee composed of people who understand the nature of the study, and the nature of the problems in the communities that are being studied," said Armstrong. "Having an Nuu-chah-nulth ethics committee will have some real benefit for the people being studied. If a drug company patented a drug based on this research, they would make millions of dollars, so there needs to be a community equity aspect of the research, so if there are financial benefits, it could help the people who were partners in the research lead a bit better life," he said.

Armstrong contacted Dr. Ryk Ward in 2000, shortly before the story on his misuse of Nuu-chah-nulth blood samples became public.

"I contacted him by e-mail and suggested he find ways to return the blood or allowing people access to the data for further research," said Armstrong. "My general purpose was to raise his awareness as to the interest amongst the people who were the subjects of the study. He responded some months later after it had hit the press, and said he was interested in ways of returning the blood. My purpose was to get him to do the ethical thing and return the blood," he said.

According to Armstrong, Ward suggested the genetic methods weren't as far advanced then as they are now, and that they weren't able to get as much information as he felt they should have been able to collect. Other researchers who worked with Ward were also disappointed they were not able to do more research with the blood and data collected, and feel there is an opportunity for more work to be done, based on their earlier work.

There is still a lingering concern that data and blood samples collected by Ward are still out there, separate from the items shipped from Oxford to the University of British Columbia.

Blood returns

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that I didn't know where my blood had gone and what the results were if any," he said. "My persistence paid off, and the [NTC] table mandated we set up a committee to deal with the blood issue, and set up a Research Ethics Committee. There were never any controls before, and our people put a lot of trust in researchers. So now we'll know who's coming into our communities, and we'll have the ability to make sure they follow our protocols and rules," he said.

Noreen John, who gave blood along with the rest of her family, is still puzzled by the 20-year silence of researchers. "There's a lot of arthritis in our family, and what I want to know is what were the results of the studies?" she said. "The Research Ethics Committee should have been in place years ago, before people started coming here researching our bodies or our lands."

"Aboriginal communities are way ahead of the game [by setting up research ethics boards and committees]," said Arbour. "They're not the only ones who want research results to come back to them, and these models are great models for all," she said.

"The Nuu-chah-nulth aren't the only people who have a research ethics committee," said McDonald, listing similar organizations across the province. "They're important because they know what's going on in the community. They know what needs to be done, and they know which proposals are just going to be time-wasters for everyone," he said. "It might delay some research, but more importantly it protects against sloppy research."

RESEARCHERS:

Will the Research Ethics Committee prevent research from happening in Nuu-chah-nulth territories, as researchers head to communities without similar boards, looking for the path of least resistance?

"We're not closing the door on research," said Baird. "There are a lot of health problems around and we want them addressed. We can offer guidance to researchers and make sure their research helps Nuu-chah-nulth. But we have to also make sure situations like to one with Ward never happen again," he said. "From now on our eyes are wide open."

There have already been research applications approved by the committee, but no one has brought forward any proposals related to the blood yet.

"I think the communities can come together and work together in a respectful way," said Arbour. "Getting to know each other and understand scientific and cultural issues is very important. These researchers have to understand that DNA is not just DNA; in many Aboriginal communities, DNA has a hugely spiritual importance," she said.

LEGAL ISSUES:

The case of the Nuu-chah-nulth blood has not only been studied by lawyers contracted by the tribal council; law students at the University of Toronto were presented with the case to write papers on.

Although incidents that occurred at the University of Utah and Oxford University are outside the boundaries of Canadian law, many legal opinions suggest the Nuu-chah-nulth could sue UBC, and UBC could then sue Ward's estate for breach of trust, breach of contract, breach of privacy, breach of confidence, and breach of fiduciary duty.

"When the initial arthritis study failed to turn up any evidence of a genetic link, Ward took advantage of this particular vulnerability to profit himself by using the DNA to help establish his reputation in an entirely different field – biological anthropology," wrote one University of Toronto law student. "Based to a large extent upon his publications in this area, that were a direct result of his research on Nuu-chah-nulth blood, he was eventually awarded a Chair at Oxford University."

For 71-year old Ina Campbell, who suffers from rheumatoid arthritis, an apology and compensation from the universities would be a good start. "I feel like I was used," said Campbell. "I really think they should apologize, and back that up with compensation. They compensate everyone else, why not us?" she said.

APOLOGY:

Many people in First Nations and academic communities have called on Oxford to apologize for its role in Dr. Ward's research.

"When they recognize the fraud they were a part of, they'll see we're due an apology," said Baird. "This story is not over. Oxford and other institutions that have our blood should come forward. UBC has been more than helpful. They've gone that extra mile, and other universities should too," he said. "Their actions speak volumes about what they think of us, and in the case of Oxford, it's not good."

"When they recognize the fraud they were a part of, they'll see we're due an apology," said Baird. "This story is not over. Their actions speak volumes about what they think of us, and in the case of Oxford, it's not good," he said.

"You would hope someone would have apologized, at being unwittingly involved in this kind of thing," said McDonald, adding that universities, including his, should have better control over such studies, and work towards ensuring similar cases never happen again. "I know [an apology] is a gesture, but it's the right kind of gesture to make when you've seen something go so wrong," he said.

"When I heard our blood went all the way to England, I was concerned," said 73-year old Gertrude Frank. "I still wonder what the findings were, and what it was all about. I still want it to used to find how to help our people with arthritis," she said. "They should have known there was no consent for Dr. Ward to take it over there. He went over his boundary. Maybe it would help us feel a little better if they apologized to us."

But Oxford University is unrepentant. The university press office maintains no further statement on the issue will be made further to a February 6th, 2004 media release announcing the repatriation of Ward's blood samples and data to the Nuu-chah-nulth via UBC.

WHAT NOW?

According to Dr. Laura Arbour, genetics technologies have advanced to the point where Ward's dream could become reality.

"I think we're leaps and bounds ahead of where we were 20 years ago, and science could help determine genetic understandings," said Arbour. "It would be beneficial to explore it and see if some good can come of it. There is some information that would be useful if someone wanted to restart the study some 20 years later," she said.

It is also possible the survey data could assist families involved in genealogical studies or "family trees", as the mitochondrial DNA (mtDNA) data shows family inter-relationships for thousands of years.

But are Nuu-chah-nulth and other Aboriginal communities protected from similar transgressions of research?

"We pride ourselves on our research outputs but we don't check to see what happens to our research subjects," said McDonald. "We honestly don't know what's going on in the field. We should be able to do audits, spot checks, and safety mechanisms. We don't do that and we really need to. Our credibility is on the line," he said.

Even though lessons learned by the Nuu-chah-nulth have resulted in the formation of a Nuu-chah-nulth Research Ethics Committee, as well as national and international legislative change, vigilance is still required.

"Unfortunately, Ward taught us not to trust researchers just like the Residential School taught us not to trust the Church," said Baird. "Hopefully the day will come when we can put it all behind us, but we've unfortunately learned a lot about the dark side of scientific research," he said. "Our eyes are wide open now."

Fisheries - ca̓-ca̓-ƛuk

High mercury levels in Black Cod

By *David Wiwchar*
Ha-Shilth-Sa Reporter

In the fall of 2002, the Canadian Food Inspection Agency (CFIA) in conjunction with the Canadian Sablefish Association set up a joint sampling and testing plan to evaluate Sablefish (also known as Black Cod) for mercury levels. The industry provided representative samples of the fishery and the CFIA analyzed those samples for total mercury levels. Sampling, testing and data analyses have now been completed, and increased levels of mercury have been discovered in fish from the west coast of Vancouver Island.

Sampling, testing and data analyses have now been completed, and increased levels of mercury have been discovered in fish from the west coast of Vancouver Island.

The two areas where the fish were sampled are known as Stock Management Areas 3 and 5. SMA 3 encompasses the West Coast of Vancouver Island, and is subdivided into 3C and 3D. SMA 5 covers the northern tip of Vancouver Island up to the Queen Charlotte Islands, and is subdivided into 5A, 5B and 5E. A total of 60 samples were taken during the Sablefish survey, and out of those evaluated, 22 were identified with mercury levels above the Health Canada tolerance of 0.5 ppm (parts per million). The results of the survey showed a large variance in mercury levels, with some fish testing up to 1.2 ppm. In SMA 5, statistical analysis shows that only a small percentage of fish were above tolerance, whereas the expected rate of samples above tolerance in SMA 3 was unacceptably high. As a result of these findings, effective December 1, 2004, all Sablefish (anoplopoma fimbria) harvested from groundfish stock management Areas 3 C and 3 D which are destined for the Canadian market must be held for sampling and testing by the CFIA to determine mercury levels. Only if the results of these tests show compliance to Canadian mercury levels, can the fish be marketed in Canada. Products that are intended for export must meet foreign government mercury levels.

Although the mercury levels identified from SMA 5 are acceptable, Sablefish from this harvest area and all other harvest areas will continue to be monitored over the next year to ensure levels remain consistent over time.

The CFIA, in cooperation with the Canadian Sablefish Association, will also continue to monitor all other harvest areas to evaluate mercury levels over time. According to Susan Schenkeveld, CFIA's A/Chief for fish, seafood and production, once the sablefish come into the processing plants, it takes only 48 hours to test the fish and clear them for shipment if local inspectors are advised of the shipment in time.

Mercury is a naturally occurring substance. Adult exposure to relatively high levels of methylmercury through fish consumption can result in numbness or tingling in the extremities, sensory losses and loss of coordination. Exposure of the developing fetus through maternal intake of contaminated fish can result in neurologic developmental abnormalities in cognitive and motor functions. Whether any of these symptoms actually occur, and the nature and severity of the symptoms, depend on the amount of exposure. Methylmercury is quickly taken up into higher organisms through the food chain and is retained in their bodies. It reaches the highest levels in large predatory fish and in birds and mammals which consume fish.

According to the U.S. Environmental Protection Agency website (http://www.epa.gov/region02/health/mercury.htm) the developing fetus and young children are a higher risk population because methylmercury in the mother's body may enter the unborn child and breast-feeding infants. Young children are at risk because their nervous systems are still developing and because of their lower body weight compared to adults. Exposure and health risks may be determined by measuring the amounts of mercury in blood, urine, breast milk and hair. Over time, the body can rid itself of some contamination. Adults who consume an unusually large amount of contaminated fish on a regular basis may also be at risk.

The CFIA monitors all groundfish and other marketable seafood species for a variety of contaminants, including mercury. As of press time, Health Canada had not issued any warnings in regards to dangers posed through consumption of sablefish.