The Nuu-chah-nulth blood samples were used to produce hundreds of academic papers on topics as diverse as HIV/AIDS and population genetics. "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 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. It’s hell.

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.

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.

Elder Cosmos Frank 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 needs 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, Nanoaimo, 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 published articles.
Blood returns continued from page 1

“I remember them coming around with a whole team, and they took blood from all my eight children. It was in the name of science, and they said 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 and father had arthritis, I knew it wasn’t really bad, and some of my children have it, including my oldest daughter who has it really bad now,” she said. “But there wasn’t much they were doing and he should have been professional enough to tell us what he was doing with our blood,” said Edwin Frank. To have a project that people 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 Scientific Department Head 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.”

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. Interestingly, the article concludes by thanking the Nuu-chah-nulth for their “collaboration.”

HOW THE BLOOD GOT HERE

When the original study about Nuu-chah-nulth blood broke in September 2000, academics across Canada and the United States were furious. It was a large-scale study, something like an 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 Health Law and Ethics at the University of British Columbia. “It has been very important that the Nuu-chah-nulth have shared their knowledge and their way of understanding 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 in 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, Chair 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 protocols involving Nuu-chah-nulth subjects, and would arrange the return of the blood samples from the Institute of Biological Anthropology at Oxford.

The committee consists of: Larry Baird (Chair), Helen Dick, Matthew Lucas, Karla Point, and Darlene Watts. “People kind of forgot about the blood study and I was the only one asking questions,” said Baird. “It bugged me continued on page 4

Ahousaht doctor works under legacy of research

By David Winchar
Ahousaht-Sa Reporter

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.

“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 disease, 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 of certain 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 intriguing, so 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 we 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 were kept 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 how they’re now amongst the Elders, is people want research to be done so their children and grandchildren don’t develop arthritis,” he said.

“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 advanced 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.
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 arbitrator study failed to turn up any evidence of a genetic link, Ward took advantage of and this 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 DNA, he 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.

“APOLGY:

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, I’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, in the case of Oxford, it’s not much.”

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“While you would hope someone would apologize, it has to be a full and open door to research, said Baird. “There are a lot of health problems around and we want them addressed. We can offer guidance towards what can be done, and some research helps Nuu-chah-nutl. But we have to also make sure situations like 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 up any proposals related to the blood yet. “I think the communities can come together and work in a more effective way,” he said. “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; we know Nuu-chah-nulth 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 have also 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

### Fisheries - ca-ca-fuk

High mercury levels in Black Cod

By David Winchar

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 monitor Black Cod (also known as Black Cod) for mercury levels. The industry provided representative samples of the fishery and the CFIA analyzed 30 fish 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.

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The two areas where the fish were sampled are known as Stock Management Areas (SMAs). SMA 2 encompasses the East Coast of Vancouver Island, and is subdivided into 3A and 3B. SMA 3 covers the northern tip of Vancouver Island, including the Charlotte Islands, and is subdivided into 5A, 5B and 5F. A total of 60 samples were taken during the Sablefish survey, and of those identified, 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 samples ranging 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 in Black Cod and data analyses have now been completed to determine if the health Canada tolerance of 0.5 ppm (parts per million). The results of the survey showed a large variance in mercury levels, with samples ranging 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 in Black Cod and Black Cod (also known as Black Cod) for mercury levels. The industry provided representative samples of the fishery and the CFIA analyzed 30 fish 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.

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