Report on Aklavik *H. pylori* Project to Leona Aglukkaq, Canada's Minister of Health

The Honourable Leona Aglukkaq visited Aklavik during their 100 Anniversary Celebrations. Health Issues in the community were discussed on April 7th, 2010, in Aklavik.

Ms. Aglukkaq was first elected to work for the Nunavummiut in the House of Commons in October 2008. On October 30th, 2008 she became the first Inuk to be sworn into the Federal Cabinet.

Rachel Munday (Nurse in Charge in Aklavik) was asked to speak about the project. At the request of Crystal Lennie from the Inuvialuit Regional Corporation, we also included a statement regarding expansion of the project to new communities. The two statements follow.

Project Overview:

The AHPP started in 2006, in response to long-term concerns of community members and health care professionals relating to the high incidence of *H. pylori* infection and stomach cancer. *H. pylori* is a bacteria known to be present in about 1/2 of all the world's population. If left untreated, some people may develop ulcers and even more rarely, stomach cancer. Symptoms resulting from infection might include pain, discomfort and digestive upsets. However, most people who have this bacteria don't even know they have it because most often it does not cause any symptoms or disease. And symptoms of stomach discomfort can be caused by other things, so if someone has *H. pylori* and stomach discomfort the only way to tell if the *H. pylori* is causing the symptoms is to see if the person feels better after successful treatment to get rid of *H. pylori*. The bacteria was only identified in Australia in 1981. Despite a lot of research around the world aimed at finding out how people get *H. pylori*, a source has not been pinpointed; because of this and observations that *H. pylori* clusters in families, researchers believe that it probably usually spreads directly from person to person through close contact.

The project started under the leadership of Dr Karen Goodman, from the UofA, a world-renowned expert on *H. pylori*. There was much consultation with the community and especially the Aklavik Health Committee during 2006/7 and the project finally got underway in November 2007 when the first set of data were collected, with breath tests starting in January 2008. The breath test is the standard way of checking for current infection with *H. pylori*. Since the project started, people have been allowed to join the project when they wished to; in total, 368 have participated in some way and 320 people had breath tests.

In February 2008 an amazing event took place in Aklavik. A team of 25 descended on Aklavik, including 7 consultant gastro-enterologists, nurses and sterilization specialists,

as well as 2 partners from Olympus Canada (the camera company that makes medical scope equipment), and set up a gastroscope clinic in the Aklavik Health Centre. All normal operations were suspended while 200 brave Aklavik individuals underwent a gastroscopy, using new technology, which allowed people to stay awake while the procedure was done, and even look at their own stomachs while the doctor was checking for abnormalities. In 20 years of living and working in the north I cannot say I have ever seen such a process take place in a remote, isolated community before, and in spite of minus 47C weather, the week went by with help from many partner organizations locally, without any real hitches and glitches.

From the breath test, the research team was able to determine that the prevalence of *H. pylori* infection in Aklavik was 58%, which is higher than what would be expected in southern Canada, which has a prevalence typically around 30%, but is similar to the prevalence in Inuit communities in Greenland, and lower than in some northern communities in Alaska. The biopsies taken from those who had a scope were examined by a pathologist who observed a high proportion of people with notable chronic inflammation and conditions associated with increased risk of stomach cancer.

In November 2008 as many people as wanted to be treated for their *H. pylori* infection were given treatment which was tailored to their specific medication needs and the results of testing their *H. pylori* strains for antibiotic resistance. The strains were cultured (grown) and tested in the laboratory of the research team's microbiologist. Following this, repeat breath tests were done, and as expected there were some individuals who did not clear the bacteria, so they were offered repeat treatment of a different kind.

There is still a need to collect data from residents in Aklavik to learn more about factors related to who has the infection and who doesn't, and we hope that this will continue during this summer.

Throughout this project Janis Huntington , with the CANHelp Working group, has been working on helping to get information and results communicated back to Aklavik residents in a meaningful way. A DVD about the Aklavik *H. pylori* Project has been developed, which the Health Committee has viewed and I'm glad to announce that Janis will be back next week to show the final version back to the community, so listen out for announcements about this next week. Janis hopes to arrive on Sunday.

The interest in this project has been so great that other communities have now approached the research team and similar research projects will be started in other communities in the ISR with the help of IRC and other territorial health departments, as well as across Yukon Territory.

Aklavik has reason to be proud that they have shown not only other communities in the NWT, but throughout Canada and the world that it is possible to do clinical research involving new technology in small isolated northern communities, as well, more importantly, that even in a small community such as this, research that is community driven.

If anyone has any questions about this project please either talk to Bob Buckle, current chair of the health committee, Crystal Lennie, IRC or me at the Health Centre.

Project Expansion:

Why are we expanding the research when we don't know the source yet?

It is rare that community health research, as with population studies in general, can fully answer research questions in just one location. Generally, community health researchers must investigate a variety of communities to fully understand a problem and develop solutions. There are several reasons for this:

- What we observe in one community may be unique to that community and may not be the case elsewhere
- What we observe in one research project may be the result of chance
- What we observe in one research project may be the result of errors in our observations, such as recording incomplete or inaccurate information, or project participants differing in important ways from the total community
- We often have too few people for calculating reliable statistics, especially if we need to compare groups of people on characteristics that may be uncommon

To further answer this question, it is helpful to review about what science tells us about the source of *H. pylori*, and how we research sources of infection.

What we know about *H. pylori* sources and transmission

Despite a lot of research around the world aimed at finding out how people get *H. pylori*, an environmental source has not been pinpointed. Much evidence shows that *H. pylori* clusters in families. Due to what the science has shown, researchers believe that *H. pylori* probably usually spreads directly from person to person through close contact. There are some factors that have been associated in many studies with having *H. pylori* infection, like the number of people living in the household, having infected family members, or residing in a low-income area.

Although science around the world has not identified an environmental source of *H. pylori*, research has not ruled out the possibility that it may be transmitted through contaminated water or other environmental sources. Clear evidence that bacteria are spread from a source in the environment requires being able to culture (that is, grow) the bacteria from the source, because this shows that the source contains live bacteria that can infect someone. Modern tests for bacteria, such as PCR, can detect the bacteria's genetic matter, but does not show if the bacteria in the source are alive or dead, so they do not show clear evidence that the bacteria in the source can infect people. *H. pylori* is a difficult organism to culture. Laboratory tests aimed at detecting the bacteria by culture

are costly and time-consuming. Despite many efforts to do so, nearly all attempts to culture *H. pylori* from environmental sources have failed so far.

How is *H. pylori* transmission being studied in Aklavik?

We are studying *H. pylori* transmission by trying to identify factors that might be associated with having this infection. We have surveys that ask people about their household environment, hygiene practices, diet and lifestyle so we can compare people who have *H. pylori* infection and those who do not to see if they differ on these factors. We are asking questions about water source and traditional foods (treated versus untreated water, for example). By asking these questions, we can learn a lot about things that might cause people to be have *H. pylori*, without having to do expensive, time-consuming and broad environmental scans to look for *H. pylori* in the environment. For instance, if we compare types of drinking water for people who do have *H. pylori* and those who do not, we can if people who drink certain types of water are more frequently infected.

As an example:

	H. pylori infection	*No H. pylori* infection
Water type A	70%	30%
Water type B	50%	50%

If we see results like this where a higher percentage of people who use water type A have *H. pylori*, this gives us reason to investigate water type A to find out why using that water source is related to *H. pylori* infection.

In other projects on water sources we have collaborators who hope to develop good tests for *H. pylori* in water, and this may add useful information, but we don't know how soon this will happen. In the mean time, collecting the survey data will help make the water testing more effective by suggesting where to collect water samples from.

Why are we expanding to other communities when work is not yet done in Aklavik?

There are two reasons for this. One has to do with statistics, and the other has to do with goals of the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group.

1) To draw conclusions from community health research studies, we need large numbers of people for reliable statistics. For example, in Aklavik we had a treatment trial, and found that, among people being treated for the first time, for one treatment type, 67% of people were cured of the infection, and for another treatment type, 77% were cured.

   However, when we look at the numbers, we see that 111 people signed up for the trial and 85 had a follow-up breath test after taking the treatment (so we did not

gain useful information from the 26 people who did not return for the post-treatment test). Of those with a test result after treatment, 71 had not been treated previously, and they were divided roughly in half on the two treatments being compared. So the percents that show treatment success of 67% and 77% are in groups of only around 35 people. With groups this small, we don't know if the difference between the groups occurred by chance, or because the second treatment type really worked better. By including more people in the trial, we can see if the percent treated successfully remains consistently higher for the second treatment. If we want to know if the treatment works better in particular groups of people, such as older and younger people, people with and without symptoms of stomach discomfort, and so on, we need even more people so the groups we want to compare are large enough. To make recommendations to policy makers about *H. pylori* across the region, we need reliable statistics that represent many groups of people from the different communities.

2) The CAN*Help* Working Group is made up of not only researchers from the University of Alberta, but also health authorities in the NWT and Yukon, and community groups. One of the main goals of the CAN*Help* Working Group is to address community concerns about *H. pylori* infection. A part of doing that is helping individuals in communities learn more about their own *H. pylori* status, and the health of their stomachs. We can do this by offer testing and then discussing the individual results with each person. Although the research in Aklavik has helped people their understand *H. pylori* in their community, it will not help people in other communities who are also concerned about the potential health problems that *H. pylori* might be causing them.

Expanding research does not mean work has stopped in Aklavik. We are continuing to follow-up with people there who were treated, survey individuals, and complete data analysis. We also plan to do long-term follow-up in the community, to learn about whether people might get re-infected after they were successfully treated.