The three 1993 issues of "Seasons" (the Spring/Summer issues are combined) address various aspects of dealing with Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) among Native Americans. The Winter issue focuses on tuberculosis (TB) and its incidence and treatment among HIV-positive individuals. "Remembering Tuberculosis" (Ernie Turner) is a personal account by the executive director of the Alaska Native Alcohol Recovery Center of his battles with tuberculosis and alcoholism. "Tuberculosis in the 90's" is an interview with Dr. Eric Goosby, emphasizing the risk of TB to HIV positive people and treatment options. In the Spring-Summer issue, "HIV Prevention in Rural Alaska" (Joe Cantil) describes both a program using telecommunications for AIDS prevention education in rural Alaska, and the Youth Leadership Symposium for AIDS Prevention, involving youth from rural Alaskan villages. "The ART Education Model: An Approach to HIV and AIDS Education Developed" by the AIDS Resource Team (ART), Incorporated, describes ART's programs in rural communities in the Midwest. "HIV Prevention for a Lifetime: Educating Our Children" (Calvin E. Twoguns) stresses communication with Native American children about high-risk behaviors. In the Autumn issue, "A Journey to Life: Native People with HIV Disease and Traditional Healing" (Marcie R. Rendon) discusses traditional healing and ceremonies as part of AIDS treatment. "Increasing Access to Care: The Native Special Initiatives Program" (Jay Johnson) describes nine grant projects involving culturally appropriate HIV/AIDS services. "It's Up to Me" (David Andrews) is a personal account by a homosexual Native American infected with AIDS. Each issue highlights the work of a Native American artist and includes book and video reviews and announcements of special events. (KS)
SEASONS
THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER
WINTER 1993
QUARTERLY

Rick Bartow
"Crazy Crow"
1991

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Rick Bartow was born on the coast of Oregon at Newport, home to a culture of fishing, canning, and lumbering (and tourism), not far from his Yurok ancestral lands in northern California. He lives today in the same house in which he grew up. Bartow’s Native American heritage clearly has played a large role in his art as a source of imagery and story, but he also acknowledges a deep debt to contemporary art, including such Native American artists as Fritz Scholder, Joe Fedderson, and Lillian Pitt.

Bartow’s own artistic and personal journeys have been molded by several factors: perhaps most important are his family heritage and the landscape in which he grew up and lives now. In addition, he freely speaks of a long dark period dominated by Vietnam service and subsequent stress and addiction, followed by a process of recovery beginning about 1980; both processes are integral to the evolution of his art. Two individuals whom Bartow credits with a particularly strong personal influence are an uncle who served as a mentor and muse initiating him into the ways of his society and an aunt who gave him his first art lessons and often has supplied him with materials. Bartow has been able to fuse all these various strands into his own unique vision, not an easily managed feat when an artist is forced in contemporary society to balance two very different cultural and artistic traditions.

Excerpted from a catalogue published by the Jamison Thomas Gallery in conjunction with the artist’s December 1992 exhibition.
REMEMBERING TUBERCULOSIS

Ernie Turner, a distinguished looking man in his early 60s, serves as the Executive Director of the Alaska Native Alcohol Recovery Center in Anchorage. He was working at a computer in his office when Anne Marie Holen of the Alaska Native Health Board arrived to talk to him about his memories of tuberculosis. The following are excerpts from his story.

I was born in Shageluk, in the lower Yukon Delta. It’s an Athabascan village. I was raised in that area, Anvik and Holy Cross. I had tuberculosis (TB) when I was a child, and it healed, apparently by itself. I had it in the right lung. And then when I was 19 I got it again in the left lung, and I went to a sanitarium. I was in the sanitarium from January 10, 1950 to May of 1953.

When I was trapping in 1949, I was out on the trapline and I was carrying a big log on my shoulder. And when I got back to the camp, I put the wood down and I hemorrhaged some blood. I thought I had ruptured a blood vessel or something from carrying the wood. I never thought of TB. In a couple of days I felt fine, so I spent the winter trapping. The next summer I went to work in the mining camp. One of those mobile x-ray units came around, so I had an x-ray. That was mid-summer. In December, just before Christmas, they notified me that I had TB. It took them the many months to tell me.

So I went to Bethel; they had a sanitarium there. They took another x-ray and confirmed I had TB, but they said their sanitarium was full and I could get on a waiting list. They thought about sending me to Sitka, but apparently that was full too. And they didn’t have one in Anchorage yet. So I went to Washington State. I had been working in the mining camp and trapping and I was making good money, so I went to a private sanitarium until the funds ran out.

It was scary in two respects. One was that I thought that everyone that got TB died. My mother died, two brothers died. In my village, there wasn’t a lot of talk about it. But we knew people that had TB. We knew that once they went away to the sanitarium, they would die. So when I found out I had it and had to go to a sanitarium, I thought I was going there to die. Having to go to a strange place was also scary. I had never been away from my village. When I got there they told me that they were pretty sure I would be there for only three or four months. They said I didn’t have a bad case and I’d be cured with bed rest and nutrition. Eighteen months later I was still in bed, and out of funds. So I transferred to the county sanitarium, Firland Sanitarium. It was miserable just laying there. I’d get backaches and bed
sores just from being in the bed for that long. For eighteen months I never got out of bed, except on a stretcher when they wheeled me in for x-ray. I had to eat laying down; they wouldn't let us sit up. You couldn't go to the bathroom.

Finally in 1953 they decided to take that portion of my lung out. That was in January. By May I was out of the sanitarium. I wondered why they hadn't done it earlier.

They advised me not to go back to Alaska. They felt life was too harsh here and I would relapse. I didn't know what to do. My whole life had been trapping and working in the mining camps. I was eligible for vocational rehabilitation, but without an education there wasn't much I could do. They trained me to be a barber, which I did for many years. I was quite successful, had a good trade, my own shop, and people working for me.

After I had surgery I couldn't go swimming because people would see the scar and know I'd had lung surgery. I couldn't tell my friends and neighbors, or people that I worked with in the barber shop that I had TB because it would scare all the customers away. It isolated you. If people found out you had it, they would shy away from you. It related you. If people found out you had it, they would shy away from you, you'd become an outcast. It didn't make any difference if you were in remission. So we kept it secret. In fact I married a girl from the sanitarium; she had TB. I didn't have to hide anything from her, but we did from all our neighbors and friends.

I always intended to come back to Alaska. My whole life, I thought some day I'll return home. Then I got a job, got married, had children, and it became very difficult. When my children grew up and my wife died, I became an alcoholic and lost my business.

That was another experience. There are a lot of similarities between TB and alcoholism. In the early days of TB, there was a lot of controversy about how to treat it, and you see the same thing with alcoholism. There are still a lot of different opinions about treating it. Another similarity is that alcoholism and TB are diseases that people are ashamed of having—they don't want anybody to know about it. I remember when I was leaving Alaska to go to the sanitarium, my dad knew the pilot of the plane. And he asked me where I was going and I was about to tell him I was going to a TB sanitarium, when my dad said, "He's going out to the States for a visit." He didn't want anybody to know that I had TB. It was kind of a disgrace instead of a disease. You got TB because you were weak, and they say the same thing about alcoholism.

I went into treatment and recovered from alcoholism and decided to go back to school and change my trade. After completing my G.E.D. and a couple years of community college, I went to the University of Utah School of Social Work for a couple years. I got a degree in Administration at Lesley College. They had a special college where you designed your own study. So I designed my study around non-profit corporations and administration.

I started the Seattle Indian Alcoholism Program in 1972. It was one of the first of its kind. I worked there for 12 years. It became a model program throughout the world. We had visitors from Europe, Australia, New Zealand, Greenland, and Norway. I made several trips to Alaska during that time. There wasn't a lot going on in alcohol treatment. In fact Alaska seemed to be lagging behind in those days, in the early 70s. I had an opportunity through the Seattle Indian Health Board to start a project, so I came up to Anchorage to start the Alaska Native Alcoholism Recovery Center.

It would take me all day to describe to you what I've learned from my experience with alcoholism. There's no way to describe the values I've gained from sobriety, the lifestyle, and other benefits—especially establishing a very comfortable knowledge of my inner self and spiritual identity—having that part of me alive that never was before.

What I learned from having tuberculosis—and alcoholism—is that there are no accidents. We are supposed to gain or learn something from every experience. My entire life changed from that experience. Rather than living in a village in the bush and being a trapper and laborer, I was taken away and put into a totally different environment. I learned about the values system of Western society. I had the chance to look at what's important to them in terms of their values, which are totally different. And I tried to live in that culture. I didn't quite fit; it was like putting a square peg into a round hole. I feel comfortable with my identity now. My identity, my culture, and my roots are intact. At the same time I've been able to accept all the changes that have come about in my life.
Tuberculosis. The word can bring fear and unwelcome memories to Native people. My mother spent two years in a sanitarium in Kentucky in the mid-forties. She had a cough that she ignored until, while giving blood for the war effort, the attendant suggested she see her doctor. Soon she was confined to a tuberculosis (TB) sanatorium. She was required to spend six long months in bed. Her feet never touched the floor. She was not released for another year and a half.

She contracted TB in the Indian boarding school-orphanage she had recently left in South Dakota.

Similar stories are true for many Native families. Because TB is increasing again in certain American populations, it is time to review the facts, and consider how to protect our communities. TB need not be the terror it once was. We need only learn the symptoms, support screening, and maintain treatment when TB is diagnosed.

TB is a disease of poverty and displacement. In this century, lack of access to health care has contributed to higher TB death rates for Native people. Psychological, economic, social, and physical environment all affect the strength of the immune system and a healthy immune system is an effective defense against tuberculosis. But poverty, poor nutrition, and substance abuse are conditions of life for too many Native people. These conditions make many Native communities susceptible to the disease.

Tuberculosis is a communicable disease that damages the lungs and other organs, if untreated. It is a bacterial infection. Unlike HIV, which is not spread casually, TB is an airborne organism that can be spread by coughing and sneezing. Poor ventilation and crowding facilitate its spread. Homeless shelters, prisons, and some other institutional settings need to identify and treat people with TB quickly.

Only a few people who have been exposed to tuberculosis will develop an active infection. Many people have been exposed to it and have TB infections, but because their immune systems are healthy they do not develop active infectious TB. TB infection is screened through the use of tuberculin skin tests. The main symptoms of active TB are weight loss, coughing, and fatigue. The illness is diagnosed by chest x-ray and sputum analysis. Active TB is contagious and requires treatment.

Sometimes people who have been exposed to TB but are not showing symptoms need to be treated. One example would be people with impaired immune systems, such as people infected with HIV. Drug treatment today is very effective, if started early and maintained.

Public health policy makers are not recommending the reopening of TB sanitariums because a person is no longer contagious when he or she begins and maintains treatment. People who have TB but are not diagnosed or resist treatment, however, are a public health concern.

The rate of TB among Native Americans and non-Hispanic whites has decreased steadily since mid-century. In spite of that decline, the rate of TB mortality for Native Americans is five times the total TB mortality rate for other races in the United States. Currently TB is on the rise among the foreign born, Hispanics, African Americans, and Asian Americans.

If TB is declining among Native people, why the concern? Tuberculosis is a disease of poverty. Native people are among the poorest in the nation. If TB is not diagnosed early and if treatment is not maintained, it can spread in a close-knit community. Also, TB has become an early complication of HIV infection. For people with HIV infection, TB can lead to early and unnecessary death.

What can we do? We can prevent TB from spreading in our communities through early diagnosis and maintenance of treatment.
RICK BARTOW
"DREAM SEQUENCE III"
1990
Tuberculosis in the 90's

Eric Goosby, M.D. is the Director of the Division of HIV Services for the Health Resources and Services Administration (HRSA), overseeing Titles I and II of the Ryan White Care Act. The Act provides money to set up continuums of care for HIV infected individuals. He has held the position since December of 1991. Prior to that he was the Associate Medical Director of the AIDS Clinic at San Francisco General Hospital for six years, where he was involved with AIDS clinical trials, and other research in clinical care issues for the HIV infected. His medical specialization is in internal medicine and infectious diseases. He was interviewed by Andrea Green Rush, NNAAPC's Information Coordinator.
The resurgence of tuberculosis in the United States has received a lot of media attention relative to other public health issues and has generated a lot of concern in the public health sector. How do you rate the current threat of TB in American society?

I think, overall, for the general population it’s low. Low risk is anyone who is not HIV positive, homeless, or from a low socioeconomic group. Those individuals are in the position of not really having much risk of contracting TB unless they are exposed to an active case. We (at HRSA) are in the position of managing HIV infected individuals and their risk is quite significant. We have been especially concerned with multi-drug resistant tuberculosis (MDR-TB). We’ve seen it predominantly in Miami and New York City, but we are quite worried about it and will be following it closely.

On the subject of multi-drug resistant strains of TB, how exactly do they develop?

There have been 233 cases of MDR-TB reported in the United States. Many of those contracting the disease have been HIV infected. The scenario that most individuals accept as the cause for the increase in the prevalence of MDR-TB is the following:

An HIV negative individual is exposed to TB, develops active TB, and is put on an inappropriate regimen of anti-mycobacterial drugs and one that is not long enough. The person goes through a scenario of being on and off INH (isoniazid), rifampin, ethambutol, and pyrazinamide (PZA) for different periods of time and develops a resistant organism by intermittent dosing of those drugs. So instead of a sustained dosing pattern, these individuals will forget it one week, take it religiously for another week, be off it for two weeks, that type of thing. That’s really where the MDR-TB comes from.

Does it spread like TB from one person to the next?

Yes. MDR-TB is spread by aerosolization of droplets that contain the mycobacterial organism itself; it is less than two microns in diameter and anything less than two microns in diameter floats on the air currents in a room. When you inhale, it gets all the way out to your alveoli in your lungs. They bypass all the filtering mechanisms that are present in your lungs. You inhale it and it goes right down through your nose, through all the sinuses, down through the trachea, and into your large and small bronchi, bronchioles, to the alveoli in one little swoop. So it’s like an express ride out to the alveolus.

In the alveolus, the mycobacteria sits and wiggles into the alveolus wall, where you either set up an immune response that identifies, stops, walls off, and kills the invading organism; or if you don’t have an immune response and it gets into the alveolus wall and begins to divide. Once it divides two or three times it gets into the wet system and drains through your lymph nodes into your blood and spreads into your blood stream and then it is disseminated throughout your body.

In an immune competent HIV negative individual you will stop it at the level of the alveolus or certainly when it gets to the first set of regional lymph nodes that drain the infected area of the lungs. And that will be the end of the infection. That individual will have a positive PPD (tuberculinn skin test) but not a history of active TB. If a person does not wall it off and successfully stop it at that point, you’ll get the continued division of the mycobacteria and then you’ll get an episode of active TB.

Active TB is when the person on the initial infection develops a non-productive cough; so that they have a cough that’s dry. They usually have a low grade temperature – 100 to 101. They will have profuse night sweats. Night sweats are sweats that will wake you up because your night gown and sheets are so wet. Once you sweat it goes into your clothing and sheets and then dries and gets really cold and that wakes you up. It usually happens two to three times a night. During the day you usually don’t have the sweats. You can advance to shortness of breath and eventually coughing up blood. In an HIV negative person it will kill you over a period of months to years.

An HIV positive person, with regular mycobacterial tuberculosis, commonly called MTB, not MDR-TB, can be successfully treated with INH, rifampin, ethambutol, and PZA in a twelve month regimen. You can also treat it in as short as six months if you continue all those drugs. If you wanted it to treat it for twelve months you would use INH, rifampin, ethambutol, and PZA, and after three months you would drop off the ethambutol, but continue the rest.

With MDR-TB in a HIV positive individual, the majority of patients will be symptomatic right off the bat. And you will have a scenario that will kill them in three
months. Nearly all HIV positive individuals with MDR-TB have died. There are some that we have identified who are still alive but they're doing poorly and we expect them to die. The usual time frame is death within three months. That is a very rapid death for TB.

HAVE ANY OF THE PEOPLE WHO HAVE CONTRACTED THE "MULTI-DRUG RESISTANT STRAIN BEEN HIV NEGATIVE?"

Yes. Of the 233 MDR-TB cases, about 180 were HIV positive and the rest were HIV negative. Of the HIV negative cases, there are sixteen or seventeen individuals that are thought to have been cured of MDR-TB. The cure came about by identifying the infected portion of the lung and the surgical resection of that portion. So it's a surgical treatment—not a drug treatment. And for sixteen or so of these people it looks like they're going to be okay. The average number of surgeries required to clear the infected portion of the lung is two.

(By the way, the drugs that are resistant are uniformly INH and rifampin. We can talk about why later.) For an HIV negative individual with MDR-TB, multiple surgical resections costs on average about $185,000. The average number of thoracotomies is two. MDR-TB has been spread to health care workers and prison guards, all HIV negative. It is an aerosolized spread. If you are exposed to it, you can be infected. It is the plague that people thought HIV was going to be. So you could literally be on the Metro (transit system) or on BART (transit system), and someone [with an active infection] can cough, and you can get infected by that. Even with MDR-TB, most people will require multiple exposures to get infected but there are many cases of one exposure resulting in an active case. But the usual scenario is that you require more than one exposure to contract it.

CAN YOU TRANSMIT THE DISEASE ONLY WHEN YOU HAVE AN ACTIVE CASE?

That's right. Transmission occurs only in an active case who is coughing. You can have active disease and not be coughing.

To return to MDR-TB, these people who are intermittently on and off therapy selectively develop organisms that are resistant to INH and rifampin. INH and rifampin are two of the mainstays in treating the mycobacterial disease. They are both cidal drugs. By cidal, we mean drugs that kill the organisms on contact, as opposed to static drugs.
Bacterial static would be a drug that is static—that stops the organism from dividing. It stops the organism from dividing and allows your own immune system to come in and fight it. So with static drugs you are dependent on an intact immune function. If you are treating someone who is immune deficient they will not adequately clear up an infection if you give them a static drug. So that is the reason why INH and rifampin are essential in the treatment of MTB in an HIV positive individual. PZA is also cidal. So you have another cidal drug. Ethambutol is static. So with a typical regimen, you have INH, rifampin, and PZA as cidal and ethambutol as static and that would eradicate an MTB infection in an HIV positive or negative person. In MDR-TB, you have essentially treated people with ethambutol and PZA, just one static and one cidal drug. Historically you don’t treat TB well with one drug. The reason you have to treat TB for so many months is because it divides about every three to six weeks. And the only time the drug works is at the moment of division. So you have to keep the drug on board long enough for the mycobacterium to divide and incorporate the cidal drug into its genetic material and kill it. And that takes weeks to months. So the shortest treatment would be six months and the longest treatment—back in the early eighties—you would treat TB for twenty-four months, then it went to eighteen, twelve, nine, and now, six.

That’s a tremendously long treatment regimen.

Yes.

It seems to me that the key to stopping the multi-drug resistant strain is through compliance with a treatment regimen. Are there any steps recommended for ensuring compliance?

Yes. The Centers for Disease Control (CDC) and HRSA put out a national action plan to combat MDR-TB in April of 1992. It is available by writing to the CDC. It's a binder of recommendations that went out to every city and state department of health in the United States. Recommendations were made on infection control, outbreak control, and patient management in terms of increasing compliance. To make a long story short, the main recommendation is that individuals should have observed therapy. At least three times a week, the person is either administered medication by coming into a clinic to have it popped into his mouth or a nurse goes out to the house and watches the patient take them. It’s very expensive, very time consuming and not very much fun for the health care providers. It’s not a very interesting job.

I imagine for people who are homeless or indigent, it must be very difficult to ensure compliance, even going to that extreme.

That’s right. The CDC was given $65,000,000 to help health departments do it.

And do they have any feedback so far?

Not yet. It’s still in early implementation.

The other question that comes up when we talk about TB and HIV has do with discrimination—whether or not we are seeing an increase in discrimination because of the TB and because TB, as you say, especially the multi-drug resistance strains could turn out to be the plague that HIV hasn’t. Do you see any evidence of increasing discrimination?

I think that homeless shelters, housing for HIV infected individuals, as well as health care delivery systems, are much more vigilant in identifying and establishing the status of an individual with regard to tuberculosis.

Once your T-cells are below 300 you may not respond to a PPD placed on your skin to identify whether or not you’ve been exposed. Above 300 you’ll react normally in forty eight hours. Between 200 to 300 it’s iffy, so most people will still put it on. Below 200 I think you’re wasting your time and you need to get a chest x-ray to rule out TB. One shot is enough. You don’t need a front and side view. You can just do it with a front view, so there’s not much radiation exposure.

So health care delivery systems that are treating HIV infected individuals, either predominantly or partially,
where there may be HIV positive people in the waiting room or have HIV positive health care providers on staff (which is very typical in AIDS clinics; in fact, there is a disproportionate number of HIV positive providers in AIDS clinics), these institutions have gotten very vigorous in identifying and establishing the PPD (purified protein derivative) status for TB of every individual before they enter their systems. That’s because of the fear of allowing an infected individual to slip in and infect all these HIV positive people who, if it is MDR-TB, have a risk of being killed by it.

They are at highest risk but even HIV negative people are at high risk. And it kills them too. I didn’t mean to leave you with the impression that MDR-TB is treatable in HIV negative individuals. The treatment is like the stone age—see if we can cut it out.

What steps do you recommend to health care workers in terms of protecting their own health?

You need to create a system which is strictly adhered to, that does not allow a patient or client to enter your system without knowing their PPD status. That means you don’t accept referrals unless they have in hand a current PPD that has been read as negative or a chest x-ray.

And how current is current?

You would not accept anything more than two months old. A lot of places say six weeks or less, but I would say two months or less and you would be fine and safe. You get up to three months and a person could easily have contracted and activated in that time. For individuals who are in the 300 or less CD4 range (there’s equivocation between 200 to 300), everyone is anergic and do not respond to the antigens. It is crucial in all HIV positive individuals that you place at least two antigens in addition to the PPD to make sure that the person is not anergic.

Should I explain further?

It would be helpful.

Anergy is a state where you don’t have an antibody response to a substance you’ve been exposed to. Let’s say
mumps. Everybody has been exposed to mumps. And you should have an antibody in your body that you made when you were a child that as an adult will give you a reaction to a skin test of mumps in your skin. You take a sample of purified protein derivative of mumps or candida (yeast) and you inject it under the skin. You will have, just like a PPD, a redness and an induration or hardening of mumps will form on the site of the injection within two to three days. That is a positive test. If you take a biopsy of that bump and looked at it with an electron microscope, you have circulating antibodies that attached to the antigen that you just injected and have brought other white cells in to clear it up. So you have an immune response (an antibody attaching, affixing complement, sending out hematotic messengers to your white cells to bring in poly's and macrophages to the area to clean up this foreign substance), initiated by the antibody. Your immune system does this with the skin test. If a person is anergic, they don’t have any antibodies circulating or their white cells don’t come into clean it up, so they don’t have any redness or a bump forming even though they have been exposed to mumps in their history.

A person who has active tuberculosis can bind up all their antibodies in fighting the TB so there’s no antibody left to react to the skin test. Even an HIV negative person can be anergic during an acute infection with TB. To make sure you are not looking at a false or negative PPD you always put on control of candida, strep, or mumps to make sure that the person is not anergic because they’re reacting to the disease. So if you didn’t react to the PPD but you had a bump to mumps or yeast we’d say that the PPD is really negative—you’re not just in an immune deficient or anergic state from responding to an acute infection.

ARE CONTROLS ORDINARILY DONE?

Controls are not ordinarily done in HIV negative people. But they are and should be done with HIV positive people. In someone who is HIV negative and you really think they might have active disease you should do controls an example being a household exposure to an active case.

ARE THERE ANY OTHER ISSUES THAT YOU THINK ARE IMPORTANT WITH RESPECT TO TB TO COMMUNICATE TO NATIVE AMERICAN HEALTH CARE WORKERS?

I would say if you are working with patients, you should have a skin test a minimum of once a year. This is a definite recommendation. People need to be very active in establishing a PPD status every six months for an HIV positive person—you should check them for TB with a skin test and controls if they are HIV positive.

WHAT FACTORS DO YOU THINK CONTRIBUTE TO THE RISE IN TB IN THE NINETIES? IT WAS PRACTICALLY ELIMINATED AND THEN IT STARTED TO BUILD AGAIN IN THE EIGHTIES.

At the end of the Vietnam war, there was an increase in immigration of southeast Asians to the United States. You saw a small increase of TB cases reported in 1976, 1977, 1978 and then again in 1985 and 1986, for what had been a declining number of cases since World War II. The reason for the first increase was immigration; and the reason for the second was HIV. HIV infected individuals didn’t bring it into the country, they were just more susceptible to the infection. So if an HIV negative individual is exposed to TB the chance of developing active disease is very low. Whereas an HIV positive individual with the same exposure the chances are about ten times more likely to develop active disease. Still low—90% don’t. So if you’re an HIV positive person and you’re exposed to active TB and we follow you over time, 90% of the time that individual will not develop active disease, but 10% of the time they will. If you’re HIV positive the chances are about 1 out of 100 you will develop active disease.
RICK BARTOW
"SALMON SISTER I"
1991
Three and half years ago in the summer of 1989, I met Stephanie Castillo, a journalist and videographer from Hawaii. She was working on a video about Kalaupapa, a peninsula on Molokai where government health authorities banished people with Hansen’s Disease, formerly known as leprosy. Her video would focus on the plight of those banished to Kalaupapa and on the inspirational Father Damien, a Catholic priest who worked with them. Stephanie and I talked about the parallels between the treatment of people with Hansen’s Disease and people infected with HIV. “The Lessons of Kalaupapa” appeared in the Fall 1989 issue of Seasons. It recounted the history of Hansen’s Disease in Hawaii, Kalaupapa, and Father Damien.

Over the years Stephanie and I kept in touch. We would occasionally touch base by phone. She told me of her growing commitment to the video, and her difficulties with funding and sponsorship. Through it all she stayed focused on her goal—to illuminate this little known chapter in history and to teach the lessons learned. So I was pleased but not surprised when Stephanie called last summer and told me her video was complete.

Simple Courage: An Historical Portrait for the Age of AIDS reflects Stephanie’s commitment and resolve. It is a beautiful and affecting film. Historical photographs illustrate readings from historical documents, personal narratives, and poetry. The documentary also features several “Kalaupapa storytellers” who speak of their own experiences on the peninsula and with Hansen’s Disease. In one instance the camera follows Richard Marks, a resident of Kalaupapa, as he docents a tour of the peninsula.

A viewer’s discussion guide is available that provides additional information on subjects covered in the video, suggestions for guided discussions, sample questions for discussion, and a reading list. The 56 page guide is in itself an excellent resource.

As to the video’s relevance to the HIV epidemic, I think Stephanie said it best: “In wanting to retell the tragic story of the banishment of thousands to the Kalaupapa peninsula and the humanizing intervention there of Father Damien de Veuster and others, my conviction in the beginning was that this historical portrait could speak to us in the age of AIDS. What I came to realize later, as the project evolved over the three-plus years that followed, is that the story had a universal voice—a voice able to speak not only to the AIDS situation but to any situation where affliction, disease or hardship challenge society to respond with Simple Courage.”

For more information on the video Simple Courage, contact:

Filmakers Library
124 E. 40th Street
New York, NY 10016
(212) 808-4980
(212) 808-4983 FAX

Discussion guides are available for $3.00 per copy from:

Stephanie J. Castillo
Simple Courage
350 Ward Avenue
Suite 106-59
Honolulu, HI 96814
(808) 834-4748
CURRICULUM MATERIALS NEEDED

The National Native American AIDS Prevention Center is conducting a survey and review of Native specific HIV curricula. If your agency has an HIV curriculum (particularly for youth) or a substance abuse prevention curriculum, please send information including a copy of the curriculum if possible to:

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3515 Grand Avenue, Suite 100  
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Please send comments about SEASONS to:  
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SEASONS
LILLIAN PITT
"WATLALAS STICK INDIAN"
WOODFIRED, CLAY MIXED
1993
My tradition, my heritage, my love for the land and the people are spoken through my work. My masks reveal my feelings about our land, trees, and animals. Ancient ones ... ancient ways. Other feelings may occur along with this love – such as concern, hope, respect and sometimes, anger and angst.

I do not profess knowing all the ancient ways. But deep down inside I know the old ways and the ancient ones are with me, especially when I walk in the woods beside the rivers and at the ocean. I feel their strength in a way I do not understand or cannot speak about properly. All I know is, it feels good when I work with clay. It is an honor and privilege to move the clay into likenesses of people, animals, fish, birds, and spirit beings. I feel their strength – it gives me purpose. It keeps me going.

A good friend told me not to lose sight of these feelings. We all must remember how precious our relationships are with the land and all of its inhabitants. He knows. I know. I hope we all know our future depends upon this respect.
HIV PREVENTION IN RURAL ALASKA

BY JOE CANTIL
ALASKA NATIVE HEALTH BOARD

THE PHONE RINGS IN THE HEALTH CLINIC IN A RURAL ALASKAN VILLAGE. THE AIDS TRAINING SPECIALIST FROM THE ALASKA NATIVE HEALTH BOARD INFORMS THE COMMUNITY HEALTH AIDE THAT THE INCLEMENT WEATHER CONDITIONS HAVE GROUNDED HIS PLANE FOR THE SECOND DAY IN A ROW. THE AIDS WORKSHOP THAT HAS BEEN METICULOUSLY PLANNED MUST BE POSTPONED. IT MAY TAKE MONTHS TO RETURN TO DO THIS WORKSHOP. THE AIDE MUST MAKE OTHER PLANS FOR PROVIDING THIS INFORMATION TO THE VILLAGE.
This scenario is not unusual for itinerant health educators and village health providers in rural Alaska. Transportation problems cost time and money, and present a barrier to fending off an HIV epidemic in rural Alaska.

The Alaska Native Health Board's (ANHB) AIDS Prevention Project seeks to provide encouragement, technical assistance, training, and materials to communities and organizations who wish to develop their own AIDS prevention projects and policies at the local or regional level. Currently, three AIDS Training Specialists cover Alaska. ANHB uses a training of trainers format, as well as more conventional AIDS 101 presentations. They have presented at numerous statewide, regional, and local workshops and conventions. Materials target grade school age children, youth, adults, health providers, and health corporation boards.

The 1990 Census counted 85,698 Alaska Natives living in Alaska: 55,000 live in 250 villages, usually accessible only by airplane or boat. Most of the villages have fewer than 500 people. While there is isolation from so few people spread out over a state more than twice the size of Texas, this has not been as much of a barrier against AIDS as one might think. While the high cost of travel does limit opportunities for rural dwellers to attend workshops and symposiums, travel to larger population centers is fairly common. Isolation and logistics have demanded a unique approach to providing AIDS prevention training for the Alaska Native Health Board's AIDS Prevention Project.

A recent survey of Alaska Native regional activities relating to HIV/AIDS found that about one-half of Alaska's rural communities have had on-site community presentations in the past two years. From our AIDS Training Specialists' travels of the past two years, two things are immediately apparent: many people know the basic facts about HIV/AIDS and the others either do not know the basic facts or have misinformation. It is also known that the rates of sexually transmitted disease (STD) in Alaska continues to be above the national average, especially in rural areas of the state. It is apparent that much more work is needed in AIDS prevention. The question is always how to reach rural Alaska on a limited budget.

ANHB needed to respond to this tremendous challenge of delivering AIDS information to rural Alaska. Even with media and health care providers providing information about HIV and AIDS, it is not difficult to imagine how complacency about the disease can be a problem in rural Alaska. Alaskan summers provide long days for gathering and harvesting. The land's natural beauty is intoxicating in all seasons. Our relatives did well to pick this place to live. But the rigor and benefits of merely providing for oneself or family in rural Alaska is so engaging that one could effectively ignore all else. The challenge is to present AIDS information in a way that would touch the existing cultural norms in rural Alaska. The ANHB AIDS Prevention Project delivered the issues in two places that are near and dear to the hearts of rural Alaskans — television and their children.

This article will discuss two ANHB programs designed to reach HIV prevention in rural Alaska. One, the Youth Leadership Symposium for AIDS Prevention, could become a model program for increasing self-efficacy in youth. The other, which ANHB refers to as RATNet, may be capable of reaching an estimated forty thousand rural Alaskans over a one hour period.

**RAT Net**: RATNet (Rural Alaska Television Network) reaches nearly all rural Alaskan villages via satellite. In February and March of this year, the AIDS Prevention Project produced three live, call-in programs broadcast over RATNet. The programs focused on issues of AIDS and HIV, women, youth, and Native leadership. ANHB contracted with a local production company for technical assistance. Joe Cantil, AIDS Training Specialist for ANHB, coordinated production with on-air guests and prepared scripts. At least three more programs are being planned for next winter.

The principle format was an AIDS 101 segment, a moderated discussion of the issues, and on the air calls from viewers. In three hours of air time (one hour per show), the operators took 85 calls from all areas of rural Alaska. About
one-fourth of these calls were heard live on the air.

Planning involved several support agencies from Anchorage and other parts of the state. Trained volunteers from Chugachmiut and Alaskan AIDS Assistance Association answered the phones. They screened for calls appropriate for broadcast, documented the age, gender, occupation, and village of the callers. They also gave hotline and other resource numbers as needed. The state Office of Epidemiology, Indian Health Service, and Tanana Chiefs Conference provided materials and support.

RATNet guests were involved in as much of the planning as possible. Ten of the fourteen guests were from rural Alaska. Of course, costs prohibited more rural guests from appearing. Guests included Georgianna Lincoln, state senator from Rampart; Penny Cordes, Office of Epidemiology; Cindy Gamble, Health Educator from Prince of Wales Island; Dr. Donna Galbreath from Mentasta; Anne Walker, Executive Director of ANHB; and Sarjus Moonin, 15 years old from Nanwalek. David Sam of the University of Alaska, Fairbanks, served as moderator.

Teleconferences, information packets, and a production meeting before the show were necessary for pointing the guests in the same direction. It was necessary to provide everyone with a common base of information. Acclimating the guests to the realities of live television was also crucial. Key is remembering you’re talking to thousands of people, while at the same time feeling as though you are speaking to a friend over a cup of coffee.

The youth took a tour of the studio before the show. They were treated like celebrities. The Native Leadership guests met at a banquet of Chinese food before the show. Activities such as these attempted to help guests focus on the topic, spark ideas, inspire thoughts and courage. For that hour, they were the voice to rural Alaska about AIDS.

The evaluation of RATNet is not complete but the feedback from the villages has been positive. Before the shows, an evaluation and request forms for copies of the tape of the show were sent all over the state. Dozens of VHS copies were sent even six months after the show. ANHB believes that one benefit of the programs is that someone viewing the show in Barrow could hear some of their concerns being expressed by a person in Klawock. It was also hoped that emphasizing basic transmission facts, community prevention strategies, and a need to emphasize and rely on Native values of protecting each other in a caring way would spark local interest in AIDS prevention. Judging from rural interest in more presentations at summer camps, board of directors meetings, and community task forces, the interest in fending off an epidemic in Alaska is flowing strong.

Youth Leadership Symposium for AIDS Prevention:
Funded by a grant from the American Foundation for AIDS Research (AMFAR), 37 students, ages 15-21, from rural Alaskan villages participated in intensive training on AIDS prevention and how to present what they learned to their communities. The Alaska Native Health Board covered all costs of attending the Symposium, including travel. Cynthia Piron, ANHB AIDS Training Specialist coordinated this program. Reverend Margaret Reinfeld, Director of Education and International Programs for AMFAR, said that the program was funded because it addresses rural areas which often are left out of the AIDS education loop because of accessibility problems and a lack of services. According to Reverend Reinfeld: “The program takes a proven strategy of peer education and applies it to a population that is geographically isolated.” She added that the program could become a model for other rural areas.

Staff from the ANHB AIDS Prevention Project and twelve health educators from around the state served as trainers. Participants completed extensive pre- and post-symposium surveys. Daily evaluations provided feedback about whether the participants were still “with” the agenda or not.

Agenda items included AIDS 101, HIV Antibody Testing, Services and Resources, Negotiation and Decision-making, Condom Shopping, “When HIV/AIDS Touches You, Your Family, Your Community”, “The S.A.D. (Sex, Alcohol, and Drugs) Situation”, “Cultural Support and Barriers to HIV/AIDS Information in Our Communities”.

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"Tools for a Creative Presentation", and "Developing Your Presentation". Also present was a panel of persons living with HIV. The presence of Native people living with the virus may have had more impact on the youth than anything else. Elders provided direction for using cultural methods in presentations.

The youth were given tools, information, encouragement, resources, and materials needed to provide their communities with AIDS 101 presentations. They were paid $25 per presentation for up to two presentations. Very nearly all the youth did their presentations and the ripple effect from their involvement in the Symposium has impacted rural Alaska. Reactions to these presentations were overwhelmingly positive. One health educator commented: "This is the most effective way to reach the young people. The peer to peer education is the best prevention method in combating the deadly disease of AIDS. The Elders were so thrilled to see a young person educating their peers. They are in full support of this type of education." Others said they were impressed by the presenters' confidence and ease with the subject of AIDS.

After the Symposium, one participant successfully pushed for condom distribution in her small rural school. Four Symposium "alumni" were guests for the RATNet program on youth. Four alumni will be invited to participate at next winter's event as staff.

This program will be repeated in November 1993. Inquiries are already coming in. It is believed that improvements can be made in last year's program. Again, many of these involve the intricate logistics involved. Just getting participants to and from the symposium site is an exercise in extreme patience and faith. Follow up procedures for the youth community presentations will also benefit from the trials of last year.

One goal of the Alaska Native Health Board's AIDS Prevention Project is to provide rural Alaska with knowledgeable presenters on AIDS prevention. Some of the logistical barriers to accomplishing that have been solved for now. In Alaska the focus is on "fending off the epidemic." What is being done to do that is what Alaska Natives have been doing forever - taking what the land will give, watching out for one another, adapting to conditions, improvising if necessary to get the same results, creating what is needed to make things work, and teaching others. This will always continue.

Joe Cantil is an AIDS Training Specialist with the Alaska Native Health Board. For more information contact the Alaska Native Health Board, 1345 Rudakof Circle, Suite 206, Anchorage, AK 99508, (907) 337-0028.
LILLIAN PITT
"WILLAMETTE WOMAN"
1989
THE AIDS RESOURCES TEAM (ART) was established in 1988. Its primary goal is to provide appropriate, realistic AIDS education for isolated, rural communities in the upper Midwest region of the United States. Since its inception ART has provided AIDS education in various forms to over 450 separate audiences. Given this varied workshop, conference, classroom, convention, and in-service experience, ART has had the unique opportunity to see firsthand the evolution of local communities in their efforts to address the realities of HIV and AIDS.
Most of us working in HIV prevention and care are aware of the changing landscape of the disease. In the early 1980s, individuals appeared to succumb quickly to the virus. Pain was associated primarily with the acute stage of the disease. Today, because of various therapies, we see a virus that has evolved into a chronic syndrome. This has implications for the individual and the community.

ART first saw evidence of this change beginning in January 1991. Since that time we have encountered many families affected by HIV at our lectures. We started meeting family members who, no matter how guarded, revealed the presence of HIV in their extended family. For these families, the face of AIDS changed from statistics and graphs to the reality of living with all aspects of the disease.

We also began to hear a change in tone of questions at our presentations. At the middle and high school level, in non-Indian school settings, questions from the student audiences tended to be quantitative and objective. But Indian and racially mixed student bodies asked more questions about the affective and feeling aspects of HIV and AIDS. With adult audiences, questions shifted from basic AIDS 101 to concrete aspects of disease progression. The standard personal AIDS "story" is no longer in and of itself sufficient to meet the current demands of HIV education.

In 1993 AIDS education must address three issues: a more sophisticated form of AIDS hysteria, the probability that individuals will encounter HIV in both the home and in the workplace, and the ripple effects of a viral infection that causes chronic pain and prolonged illness. ART has developed a culturally appropriate educational approach to address these issues. We call this approach the "Second Phase."

We use the following materials in our presentations: a blackboard and flip-chart; samples of western HIV medications; elements of Native American medicine; and kits of HIV testing materials.

We use a classroom setting, and prefer to present to an audience no larger than 150 people. Audience members should be prepared to make full use of their physical senses, including sight, taste, touch, smell, and hearing. We provide a continual question and answer forum. The optimal time frame for our presentations is from one to three hours, including breaks.

There are some truths about rural lives and audiences that we try to address in our presentations. We will consider each one in turn and describe how our presentations address them.

- Audiences in rural communities and on reservations have varied reading levels. Our approach is to use the traditional method of oral teaching. We use a talking circle, alternating speakers to reach a greater listening audience.

Because a rural audience may have a reading level that averages around the third grade level, printed material may be problematic at best. We recommend using traditional teaching methods to bridge the gap between the available information and individual comprehension. Oral presentation works best, particularly what we call the revolving speaker or quasi-talking circle method.

We find that by rotating speakers we are better able to hold audience attention. In addition, if an audience member has difficulty hearing a message from one speaker, a second speaker can provide an alternative way for the audience member to "hear" the message. Another benefit of this approach is that it allows presenters time to sit back, adjust, and judge audience responses; it also prevents individual speakers from becoming physically taxed.

Individuals have been saturated with information on HIV and AIDS in various media and formats. We liken the indifference people feel about HIV and AIDS information to a kitchen clock that, when new, ticks loudly. After a short period of time, people adjust to the ticking and it goes unnoticed. Our approach is to acknowledge and engage the five senses in teaching and learning about HIV. We use a "show and tell" approach.

In most AIDS education forums only seeing and
hearing are engaged. Therefore only two-fifths of the senses are employed in learning. What about the smell of AIDS? What about the feel of AIDS, or the taste of AIDS?

ART has collected various western and traditional medicines used to combat the HIV virus. We pass around samples of AZT, ddl, pentamidine, and others. We relate appropriate, real-life stories about each of the medications — be it western or traditional herbs. During our discussion of universal precautions we distribute latex gloves. During our description of safer sex practices we distribute flavored dental dams. This method allows the audience to "touch and smell" AIDS while seeing and hearing information presented using graphs, flip-charts, and the blackboard.

ART realizes that as individuals we each carry biases in learning that we develop as we grow. For some people touch is more easily understood than hearing or seeing. For others, taste is paramount to learning. We seek to address these biases by providing a varied learning experience.

People with HIV and AIDS live longer and more active lives. Our approach is to define the syndrome as a spectrum. We use alternative definitions to help the audience conceptualize the disease differently. For example we might give a definition of "diet control" found in a book about AIDS care: "the use of food intake in smaller, more frequent amounts allows your digestive system to not overtax your body's energy reserve; but rather, to assist your body, coupled with properly taken medication, in keeping both a reserve of energy and an ability to function properly, in combating the virus' spread ..." We contrast this definition with one of our own: "eating those foods which, your body tells you to eat, both in selection and quantity, thereby allowing you the opportunity to more fully experience today and today's gifts ..."

In addition to these redefinitions, we use the blackboard or flip-chart to illustrate the changing nomenclature of AIDS. We trace the changing terms from the late 1970s to 1993, including GRID, HTLV, LAV, ARC, HIV, and AIDS. This allows the audience to see that our understanding and the definitions can and do change.

Traditional and spiritual aspects of life are part of the eternal balance. Our approach is to divide the aspects of HIV and AIDS into recognizable, traditional elements. We use the four directions of traditional balance to describe the disease and to teach the language of AIDS.
ART charts the course of HIV from asymptomatic to symptomatic to AIDS to probable death. Then we explain this progression on four levels: spiritual, psychological, physical, and social. Using a blackboard we draw parallel lines for each of these levels. Then for each level we describe how it parallels the progression of the disease. For example on the physical level we show the declining T-cell counts and the physical manifestations associated with it. For the social level we show the continuum from denial to anger to bargaining to grieving to acceptance.

We find that a social worker or social service agency employee may be able to understand HIV better on the social level; a medical professional may be better able to relate to the physical level: Seeing the parallel levels reinforces their understanding and provides insight into the disease progression on the other levels.

AIDS HYSTERIA IS STILL COMMONPLACE. Our approach is to acknowledge the traditional aspects of Native American society, by teaching a cultural reinterpretation of the illness. We do not confront hysteria directly; we feel that does not produce meaningful change. Instead we remind people to draw upon their culture and traditions.

One way we reinterpret the disease is to liken it to aging. We point out that the progression of the disease mirrors the aging process. The onset of opportunistic infections and the physical appearance of people with AIDS is reminiscent of “old age.” In addition many people have observed that people with AIDS mature rapidly and develop wisdom beyond their years. Therefore to counter hysteria, ART reminds its Indian audiences of the cultural belief in respect for all elders. If being an elder is viewed only in years of age, it ignores the physical, mental, and spiritual aspects of being an elder.

We also remind people that medicine people sometimes reinterpret illness or symptoms as an opportunity to regain the balance of life. Illness or disease need not be viewed as negative or “a curse from God.” AIDS should be placed in all healing ceremonies along with all other illnesses. In this way, the idea of the medicine man or woman accepting HIV and AIDS is presented.

Another way in which we employ culture and tradition to combat hysteria is to remind people of the prophesies and foretelling of the medicine people. Foretelling and prophesies provide a reason for coming events and possible solutions. ART reminds its audiences to look to traditional legends and ceremonies to find the balance to fear and hysteria.

These are some of the approaches ART has employed successfully in working with rural, Indian audiences. We hope that our experience will benefit other HIV educators working in rural areas.

Today Native Americans are confronting one of the most devastating diseases to strike our people, HIV disease. HIV knows no barriers in its ability to destroy one's immune system. For the most part Native Americans, especially those who live in cities know the information about HIV; but many are still naive about their lifestyles. As I reflect on this epidemic and its impact on the Native American community, I find myself thinking about Native American children, about their need for education, support, and resources.

I believe that, by and large, Native American children respect their parents. Unfortunately, if the parent is abusive or has a drug or alcohol problem, the child has a "high-risk" role model to follow. When a child models the high risk behavior of his or her parents, that child is also at risk of contracting HIV.

Our children depend on us as parents to lead them to the right choices. If we do not, our children will lose trust. Trust is a simple word and it is the main focus of children. Their very future rests with us. We must be able to build trust and teach them the wisdom they need to make wise choices.

The age at which we teach our children is crucial. Just as there is a certain time when we must vaccinate our children against disease in order for them to stay healthy, it is the same with educating them about HIV and high risk behavior. Children are very responsive to those they trust. Even young children (six or seven years old) remember the lessons they learn. These lessons should include accepting themselves and their sexuality and orientation (whatever it is). We need to help our children develop positive self-image and self-esteem. This is not a one time effort. We must continually reinforce this message. The tolerance and wisdom of Native American elders should also be reflected in the learning process.

The organizations and agencies in our communities that work with children are integral to this effort. They can create safe places for children to talk about their problems,
especially problems they face at home with their parents. If children learn to address problems in this way when they are young they will grow to be stronger children and adults. We need to build a support bridge for times of crisis, so that no Native child will go through a crisis alone.

As a two-spirited Native American I think about what support and resources are available to two-spirited youth. If a teen goes to a peer and reveals that they are gay or lesbian, that peer should not put them down. They should offer support and understanding. It is a sad fact that young people turn to alcohol and drugs, or even to suicide because they are gay or lesbian. Agencies, on reservations and in cities, that work with Native American youth should support two-spirited youth and help them understand their sexuality.

There is also an important role for Native people living with HIV disease to play in the education of our children. Native people with HIV coming forward to do public speaking and HIV education can help break down the denial that still exists in many of our communities. When I do public speaking I stress the need for behavior change. When I speak to children I explain that just as we eat good food to stay healthy, we also use condoms to stay healthy.

I have had the opportunity to speak to people in rural communities and on reservations who did not believe that there are Native Americans infected with HIV. When they hear about the behaviors that put them at risk, and hearing it from an HIV positive Native American, many decide to get tested for their own peace of mind. I also speak about the need for people who are already infected to care for themselves and love themselves.

Now is the time to address high risk behavior in our communities. We have an opportunity to make a difference to those around us. Our very existence as a people depends on how well we educate our young.

Calvin Tuvguns (Seneca) is HIV positive and lives in San Francisco, California.

This article was made possible in part by a grant from the Paul Rapoport Foundation, Inc.
EDITOR'S NOTE:

Please accept my apologies for the delay in publication of the Spring/Summer 1993 issue. I had to put Seasons and other projects on hold in order to meet deadlines on major proposals. Thanks to those of you who called or wrote. Although it's good to know that Seasons was missed, I will try to publish future issues in a more timely fashion.

Andrea Green Rush, Editor

“AN INTERRUPTION IN THE JOURNEY”

“An Interruption in the Journey” is a video that focuses on long-term, quality survival with HIV disease. It was developed by the AIDS Survival Video Project (ASVP), a Twin Cities based multi-cultural collective of six men and women who are all long term survivors living with AIDS, in conjunction with Mona M. Smith and Skyman/Smith Associates.

Primarily intended as a resource for the newly diagnosed and their families, friends, and caregivers, the video will also be a valuable resource for medical, mental health, and pastoral care professionals working in health care delivery and training programs. Among the topics covered are the participants’ initial reactions to their diagnoses and their strategies for coping and promoting wellness. Also presented are models for personal enrichment, “co-doctoring”, spirituality, support systems, and varied holistic health care options.

Although the video is not Native specific it does feature Carole LaFavor, an Ojibwe woman with AIDS. For price and ordering information, please contact the AIDS Survival Video Project, c/o Carole LaFavor, 3932 Oakland Avenue, Minneapolis, Minnesota 55407, (612) 822-3042.

“MOVING TO THE MOON: SHARING THE STORY OF HIV”

Personal letters telling others about positive HIV status are sought for a book tentatively titled “Moving to the Moon.” The anthology is being compiled by Meg Umans, who edited “Like Coming Home: Coming-out Letters,” published in 1988. “Moving to the Moon” is adapted from Paul Monette’s analogy of living with HIV as “living on the moon — entirely different environment and lifestyle.”

Contributors are welcome to use a pseudonym, but Umans will need to have real names and addresses. Letters may be edited for clarity and privacy. The deadline for contributions is December 31, 1993. Contributors should include a self-addressed stamped envelope if they have questions or would like acknowledgment of their contribution. Payment will be a copy of the published anthology.

For more information, or to make a contribution to the new anthology, write to: “Moving to the Moon,” 2447 East Coronado Road, Phoenix, Arizona 85008.
SEASONS is published quarterly by the National Native American AIDS Prevention Center.

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NATIVE AMERICAN AIDS CASES
Source: CDC reported cases through March, 1993

TOTAL NUMBER OF CASES: 569
Reflects the new definition of AIDS

SEX OF NATIVE AMERICAN AIDS CASES:
Male 85%
Female 15%

TRANSMISSION CATEGORIES FOR AIDS CASES

AGE OF AIDS CASES

SEASONS was supported by grant number H62/CCH 903122 from the Centers for Disease Control (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.
"My work represents my own impressions and experiences from a cross-cultural, bilingual point of view and expresses my experiences, my life, my faith and my convictions. I was trained and rooted in the Inupiat Eskimo tradition. When I was eleven, my family moved from the most northerly native village in Alaska to Anchorage where I learned to speak English and was introduced to western culture. My artistic expression draws from childhood memories, interpersonal relationships and spiritual faith, together with values, emotions and conflicts derived from cross-cultural experiences."

Susie Bevins
Quimmiqsaq
When we are born, we know our purpose. We are dedicated to life. Sometimes we forget that. Alcohol, drugs—we get lost and confused. We forget our purpose. To heal, to recover, we need to rededicate ourselves to life. It’s sad. It’s something we come here knowing but forget.” These are the words of one of the elders interviewed for this story.
For Native people HIV is one more disease in a line of many that threatens our survival as a people. Early Europeans brought disease unfamiliar to the tribal peoples of the Western hemisphere. Several Eastern tribes were decimated by outbreaks of influenza. In the 1800's, smallpox infected blankets were given to tribes in a planned genocidal military campaign. More recently Native people have battled tuberculosis and continue to fight alcoholism, diabetes, cancer, and heart disease.

As Native people battled these illnesses our medicine people were being silenced. Western religion, legislation, and education were forced on our people with the message to ignore our spiritual elders. At a time when we were being inundated with sickness, the very ones who could help us were being cut off from us.

In many communities our elders were ostracized. Many were labeled schizophrenic, mentally ill, witch doctors, or trouble makers. Some were sent to prisons or mental institutions. Others went into hiding for their own survival, preserving the information that is sacred to us. They knew that the prophecies foretold a return to the natural ways.

Increasingly Native people with HIV are turning to those elders who have been doctoring, healing, holding ceremonies, and keeping traditions alive to supplement or replace Western medicine. Amos Owen, a Dakota elder who died in 1991, was one of the first elders in Minnesota to take Native people with AIDS (PWAs) into the sweat-lodge and give them healing herbs. It was his belief that Mother Earth takes care of everything. He said: “I’ve seen flowers bloom in January, right out of a snow bank ... what is needed is provided.” That is the core belief of all of the elders interviewed.

The elders interviewed for this article requested anonymity. To protect their privacy, the Native PWAs asked that only their first names be used. Traditional healers did not identify themselves as healers, saying: “I am a helper.” “Don’t use my name; for the work that I do, I need to watch my ego.” “The work isn’t me.”

One man gives this message to people seeking help: “The search for help is part of the healing journey.”

A Potowatami elder says, “If someone brings me tobacco, if someone has their Native name it makes it easier to use the natural ways. The naming ceremony could be part of the healing process. The journey to know your family tree and your clan can make you feel better about who you are. Then you have some strength to fight off the disease.”

What should Native PWAs know about approaching traditional healers for help?

Carole, an Ojibwe PWA, didn’t know what to do the first time she attended a ceremony. She asked the elder what was expected of her and he told her. For Carole, it is also important that she does everything she is told to do. While visiting the Southwest, a group of White Mountain Apache women gave her some medicine with very specific instruction on how to make the medicine and how to take it. “They went to a lot of trouble to help me. So I did what I was told. I put my faith in them.”

Another PWA, Willie, who is Lakota, was also shy about going to a traditional healer. In 1988 he was very sick. He was sleeping nearly fifteen hours a day. He had uncontrollably high fevers and constant diarrhea. When his girlfriend first approached him about getting doctoring, his first excuse was that he didn’t know how to make tobacco ties. His second excuse was that the diarrhea he was experiencing would make it impossible to stay through the entire ceremony.

At the home of the elder, his girlfriend helped him make the ties. When the ceremony started he was smudged with cedar smoke. At that point he recalls an overwhelming feeling of lightness and knowing that his sickness was gone.

Despite his earlier fears that his sickness wouldn’t allow him to sit through the entire ceremony he was able to do so. Although he was not cured of AIDS, the sicknesses that accompany the disease were alleviated so that he could live a fuller life. Both Carole and Willie began a journey to life. When they felt they couldn’t go on, their families and friends provided invaluable support.

Carole’s friends took her to a Lakota healer. In Spirit Ceremony in pitch darkness, songs were sung, prayers said, and the pipe was passed. As dawn came Carole was told certain rituals to perform and prayers to say. “I was told that at the end of seven days I would know whether I
would live or die. Also, that if I was to live, I would have a clearer picture of why I would live. At the end of the seven days I realized I knew how to die. That's what the addictions were about. It took me several months to know how to live. It takes time. It's a process, a long journey.

From that initial ceremony, Carole knew that one of her roles was to talk to other people about HIV and AIDS. Since then she has traveled extensively telling her story. "If by telling my story, I can help prevent one person from contracting this virus I will feel like a success."

Carole contracted HIV through injection drug use; Willie contracted it through heterosexual sexual activity.

A Dakota elder says, "AIDS is not a gay disease. The illness doesn't discriminate. There are pieces of the puzzle we don't understand. Traditional healers don't have all the answers, but collectively we can help. When we doctored Carole the healing involved four men. We encircled the patient spiritually and did different parts of the healing."

He continues, "Western medicine only treats the physical. As a spiritual people we are part of the earth. Every plant has a root, stem, leaf, and branch branches. We have physical, spiritual, emotional, and mental parts. As Native people we need to get back to the core of who we are. The spiritual part has a healing quality to it. It gives us motion to live life at its fullest."

"What this disease has taught me is that life is an instant," Carole adds. "There is a Blackfoot saying I like to quote: 'What is life? It is the flash of a firefly in the night. It is the breath of a buffalo in the winter time. It is the little shadow which runs across the grass and loses itself in the sunset.' That is what I've learned. The chemical dependency and this illness are interruptions that helped me to stop and redirect my life."

Since that first ceremony Carole's spiritual direction has come from many people: Lakota, Dakota, White Mountain Apache, Potowatomi, and Ojibwe. No one has refused to help her. She feels sad when she hears stories of people being refused spiritual direction and healing. "I think the two highest risk behaviors we can engage in are ignorance and hysteria. Out of ignorance we engage in all kinds of high risk behaviors. Out of hysteria we can alienate people who are sick right now," Carole says.

Traditional elders are not immune to the fear surrounding HIV disease. Two of the people who helped Carole, admit to being afraid when they first heard of AIDS. To quiet their judgmental attitudes and erase their tears, they educated themselves about the disease. HIV is spread by blood, semen, and vaginal secretions. In the sweatlodge the minuscule amount of virus in a person's sweat will not spread the virus. Sharing the pipe or passing the water cup will not spread the disease.

"We need to get out of our denial about this disease. It isn't just a white disease or a gay disease. I think of my family. No one is beyond reach," advises an Ojibwe elder.

Her husband adds, "I see some Indian people treating this the way white people used to treat leprosy. They see it as something really bad and won't have anything to do with that person—they won't even speak about that person. People are afraid, and we need to take this disease seriously. There also needs spiritual acceptance.

To prevent the further spread of HIV, Carole believes some changes in spiritual practices are essential. Anytime there is the possibility of exchange of blood, changes need to be made to protect people. She advises sundancers to have their own piercing kit. Others do not agree; some argue that the power of the ceremony protects sundancers. Nonetheless many sundancers are taking precautions.

One thing people on both sides of this controversy agree on is that Native people in rural areas and on reservations need more resources and education on HIV. Willie and Carole both spend many hours educating other Native people about HIV and AIDS. Carole says, "You can't live a lie, either to yourself or out in the world, and hope to have any kind of life. For your own good you need to talk about the disease."

Willie's first public acknowledgment of being HIV positive was at Crowdog's Sundance on the Rosebud Reservation. He was moved to tears when over one hundred people stood in support for him, while Crowdog pierced for him. Since that time many of the old families sense when his illness is taking a turn and bring him medicines.

If healers just named the plants that Native PWAs
People have to reach out. It is a healing journey by itself to seek out help. The medicines will always be there with you. It is a personal relationship with the medicine. You always have to acknowledge that medicine for the healing to continue.

"It is the medicine, the ceremony, and whether the person is sincere," that are key to healing says the Lakota elder. "A long time ago the person would work for a long time with a healer ... Today, so often, the patient doesn’t take the time to build the relationship with the healer."

He continues. "Nature speaks to us to heal us. We don’t listen. The spirit talks to you from the heart. So many times we deny it."

That sentiment is echoed by the Dakota elder: "A lot of people are walking around with no soul, a piece of them is missing. People are looking for a friend, validation, or some kind of acceptance."

Traditional ceremonies and healings can be a place for PWAs to share their doubts, a place to be free to be themselves, and a place to share what is positive. The ceremonies can also be a place where their families and friends can participate in the healing process.

In the early 1970s traditional elders in South Dakota had visions of a disease that was coming for which there would be no cure. The message in the vision was more important than the vision itself. The message was that AIDS is not here for its own sake. It is here to give Native people the opportunity to get their act together for what may be coming next.

One of the elders interviewed says, "We need to know why we are here. We are here to learn and to leave something behind for future generations. To my nieces and nephews I say: take control of your lives, know what you are doing, stay away from alcohol and drugs, be good warriors, and don’t be afraid to learn."

Carole reminds Native women of the Cherokee saying: "A nation is not conquered until the hearts of its women are on the ground." "As a parent there were times I would not have gone on if not for my daughter. I am most touched by youth in my travels. They really are our future. That is not a cliché. They really do rely on us to keep them safe. We need to talk to them about sexual promiscuity and chemical dependency. Unless we tell them, they won’t know what is dangerous and what is not. Willie’s advice is to ‘love yourself enough to think things through. Go ahead and experience life, you’re going to anyway, but remember to think.’ Willie and Carole are living their journey.

There was a time in our cultures when death was accepted as as much a part of life as birth. Stories passed from generation to generation tell of elders knowing when they would die or of people striving to complete a particular task before taking the journey to that other world. These people lived their lives in the moment, performing tasks the Creator sent them here to do.

Carole says it eloquently. "I’ve always been a spiritual person. Spirituality is the opposite of addiction. I am not afraid of death. The spirit campfires on the horizon at sunset are waiting for me as well as for others. Grandmother explained that it is like a thin veil. People in the other world can see us. They are always with us. And while we can’t see them, if we hold that vision in our mind, we know they are there and can feel their presence."

Marcie Rendon is a Writer and is enrolled at White Earth in Minnesota.

This article is presented in collaboration with the National Indian AIDS Media Consortium.
INCREASING ACCESS TO CARE: THE NATIVE SPECIAL INITIATIVES PROGRAM

BY JAY JOHNSON,
DIRECTOR OF CLIENT SERVICES,
NNAAPC

THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER (NNAAPC), with funding from the Health Resources and Services Administration, has awarded nine grants to Native American programs throughout the United States. The Native Special Initiatives Program is funded under the Ryan White CARE Act. These projects will either provide case management to Native Americans with HIV infection or plan for the provision of HIV-related services in their communities. A group of Native people from around the United States advises the administration of the Native Special Initiatives Program. Awards are around $50,000. The projects will run from September 1, 1993 to August 31, 1994.

In Anchorage, Alaska, Chugachmiut will provide case management services to Alaska Natives in the Chugach region who are HIV positive or living with AIDS. In addition, they will develop a needs assessment of HIV/AIDS clients and their families to assist with community planning and program development.

The Indian Community Health Service will conduct a comprehensive survey of HIV/AIDS services available to the Native community of Phoenix, Arizona. The survey will assess the availability of culturally relevant services, barriers to service, and the needs of Native American men, women, and children infected with HIV or at high risk of contracting the virus. Information from the survey will be compiled into a “Strategic Planning Document” for dissemination to the Native American community to assist in planning and development of HIV services.

The Indian Health Council, Inc. will provide biannual countywide traditional Indian health retreats to Native Americans infected and affected by HIV/AIDS in San Diego. The health retreats will increase access to
American Indian traditional and spiritual leaders who support HIV/AIDS services, prevention, and education efforts. Self-maintenance and self-esteem will be stressed and follow-up with traditional healers will be supported and advocated.

The Milwaukee Indian Health Centers will provide comprehensive, holistic, and culturally specific services to HIV infected and affected American Indians in Wisconsin, through a collaborative, coordinated, culturally competent, and family-centered care system. This will be accomplished through expanded outreach to the American Indian population, including HIV testing and counseling; providing primary health care, case management, referral, and counseling services to Milwaukee-based HIV positive clients and their significant others; providing traditional culture in the model of care; establishing collaborative agreements with the eleven tribes in Wisconsin to address gaps and barriers in service created when clients move between the reservation and urban center; and coordinating care for tribal clients.

The Native American HIV/AIDS Coalition will conduct a needs assessment and health survey for Native Americans living in Kansas City, as well as four rural Kansas tribes. The assessment and health survey will help determine HIV status and compile a range of statistics including HIV prevalence and progression, other STD infection rates, frequency and prevalence of HIV counseling and testing, and determination and assessment of high risk behaviors and groups. This information will be used in the development of HIV education and program planning to meet the needs of Native Americans.

The Navajo Nation AIDS Network will expand their HIV/AIDS education efforts by implementing an outreach program for HIV infected and affected Navajos and their families. Increased education efforts in the rural community will inform tribal members of HIV infection, transmission, prevention, and services available on the Navajo reservation. Additionally, support groups will be formed based on input from the community.

Papa Ola Lokahi will conduct a client and provider needs assessment of the Hawaiian community. The needs assessment will be analyzed and incorporated into a service plan report which will detail how existing groups can work within the current service structures to better serve the Hawaiian population. This will include workshops, meetings with the Native Hawaiian health care systems, and new liaisons for support and outreach services. The target population will be Native Hawaiians with HIV/AIDS in the State of Hawaii, and their families.

The Tuscarora Tribe of North Carolina will facilitate the planning and development of culturally specific HIV/AIDS services for Tuscarora and Lumbee-Cheraw Indians living in a rural, non-reservation area of southeastern North Carolina. They will conduct a community-wide, four-tiered needs assessment survey to determine the normative, felt, expressed, and comparative needs of the proposed target population. Results of the survey will be used to design a culturally appropriate HIV/AIDS client services model that will address the unmet needs of the target population.

The Seattle Indian Health Board (SIHB) will expand its delivery of services to Native Americans infected with HIV/AIDS. SIHB will target Native Americans with HIV and AIDS for case management services, with special emphasis on providing case management services for males, an underserved group in the Seattle area. A speakers bureau will be available for public presentations on HIV/AIDS prevention, treatment, sources for emotional and peer support, and case management services:

The Native Special Initiatives Program will assist Native American communities to plan and develop HIV/AIDS services that truly meet their needs. These programs will be models of culturally appropriate HIV/AIDS services.
What can be said about AIDS that hasn’t been said before? For me it is the role of the break-up of the traditional family. When a child is raised by a single parent the child will eventually seek out the missing component in their life. If a son is raised without a father or without a male role model he will almost inevitably search out the missing role model to discover parts of himself he doesn’t quite understand. I was married for six years and have a daughter who is eighteen years old. While I still love my wife and child, the marriage didn’t work out. As a child raised without a father I sought out the masculine qualities missing from my life. In my case this search lead to the gay community. Love from a masculine figure fulfilled my search for the missing piece of the puzzle.
I believe that at the core of homophobia is the fact that gay men reflect both masculine and feminine qualities. Heterosexual men are afraid to see the feminine side of themselves, because society has taught them that femininity is weak. This is the greatest misconception of all. There is great strength in our feminine side.

Reflecting back when I was young, it was difficult to accept that I was different. Most of us realize this as children. Some hide it. Others do not. It is easy to hide if we choose to. I believe this is why some straight people are so hostile when loved ones “come out.” They feel fooled and foolish that they did not see it all along.

What I love and value about being an American Indian is that our people have always accepted homosexuals as being special. Homosexuals or two spirited people were revered as people with special power. I believe this was a direct result of honoring their feminine side. With the realization that we are special comes the belief that we do not deserve to be treated like second class citizens. Many of us have already worked through the self hatred brought on by being “different.” Most of us have realized that prejudice is created by ignorance and fear. This is why I quickly learned when I first came out, not to internal the hostility of others.

How do I feel about HIV and AIDS? I was talking to a friend who has AIDS, and I asked him what he thought his family’s reaction would be when he died. He replied: “They will be dancing in the street.”

I said: “You mean they will be glad your dead?”

“No,” he said. “They will be happy I’m in heaven.”

This conversation changed my perspective forever. When I was diagnosed with AIDS, the doctor was afraid to tell me the truth. When he did I think he was surprised by my reaction: “Thank God, I’m almost out of here!” In my heart I knew my lessons were almost learned.

I view death as a rebirth into another form of life. I believe life is a series of choices and we act out the choices presented to us. Life passes quickly and in the end there is death. There are no exceptions. In my case I was given a warning, a wake up call that has allowed me to tie up all my loose ends. When I was young I was a fighter. I was a punch drunk, drug addict. I would get into fights and hold a grudge for years. I rarely go to bars now, having realized that life is a valuable thing—like money the less you have the more important it becomes.

How do I feel about my daughter and leaving her behind? She has equipped herself with a good education. It should help her fight the battles she will face. She is registered with our tribe and I feel we of the Walker River Paiute Tribe have learned the value of “economic development.” We have capable women in power who understand leadership and have definite goals. Our tribe has witnessed our chairwoman’s achievements and we stand behind her. This is why I know my daughter’s future is in good hands.

It is also a good example of the strength of women. We have had men as our leaders, but when a woman was given the position of tribal chairperson, our tribe excelled.

I have not been a part of my daughter’s life since she was five years old. Like her, I grew up without a father. I met my father when I was a teenager. It raised many questions for me. When I was a child I wondered: “Why did you leave me?” When I eventually met him all of my questions disappeared. I knew he had his own nightmare to contend with. I told him: “Thanks for getting me here, now it’s up to me to do the rest.”

My best advice to young Native Americans is that we are all born alone; even if our family ties are strong, we must take responsibility for ourselves. We, as young people, should use our God given talents to create a better tomorrow and to honor our elders.

David Andrews is a person with AIDS, and lives in Sacramento, California.

This article was made possible, in part, by a grant from the Paul Rapoport Foundation, Inc.
World AIDS Day 1993: “Time to Act”

The World Health Organization has chosen “Time to Act” as the theme for World AIDS Day 1993. It is a rallying call for urgent action against the HIV/AIDS pandemic—not only on World AIDS Day, but every day of the year.

In 1993, as the pandemic continues to spread, it is...

Time to fight denial, discrimination and complacency among governments, communities, and individuals.

Time to bridge the deepening resource gap.

Time to reduce the vulnerability of women to HIV infection by improving their health, their education, their economic prospects, and their legal and social status.

Time to provide the young people of this world with the knowledge and means to protect themselves from infection.

Time to set up strong prevention and education programs in the workplace.

Time to ensure that humane care for people with HIV and AIDS is available everywhere.

December 1st is World AIDS Day, but the spirit of that day must resonate each and every day until the pandemic is ended.

Walking On

Two Native Americans with HIV passed away recently. Each was active in HIV prevention education. In 1989 Walter Ketah appeared in the HIV prevention video “Circle of Warriors.” More recently he was an HIV educator with the AIDS Resource Team, which provides HIV education to rural and reservation communities.

Before his diagnosis with AIDS, Joshua Ruiz worked on an elite fire fighting team, the Hot Shots of the California Department of Forestry. When he could no longer fight fires, Josh turned his energy and commitment to educating people in rural, Northern California about HIV and AIDS. His voice and commitment will be missed.

Please send comments about SEASONS to:
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NATIVE AMERICAN AIDS CASES

SOURCE: CDC REPORTED CASES THROUGH SEPTEMBER, 1993

TOTAL NUMBER OF CASES: 731
Reflects the new definition of AIDS

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TRANSMISSION CATEGORIES FOR AIDS CASES

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