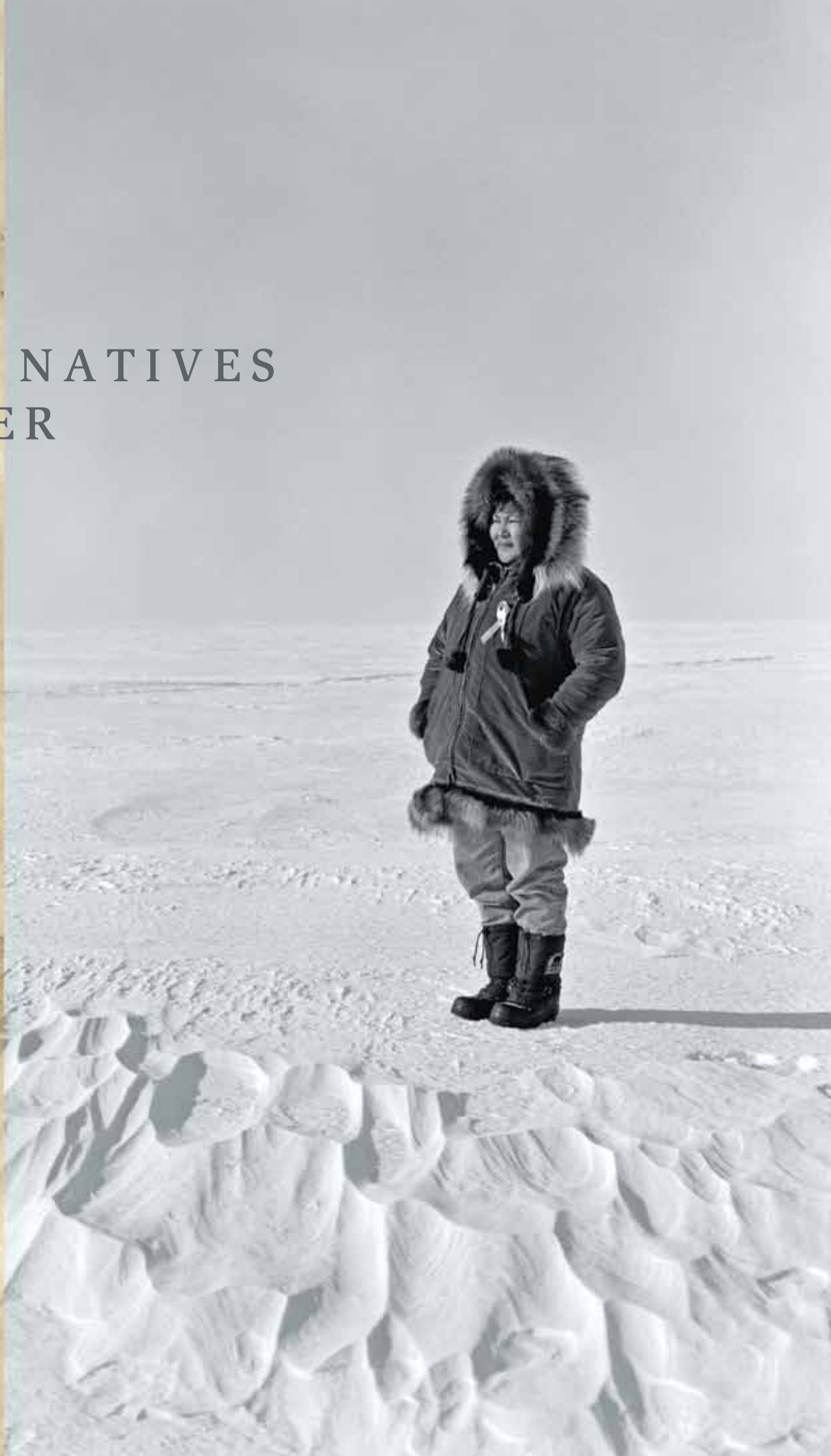
ALASKA NATIVES & CANCER



ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

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Cover photo: Ruth Nelson, Kotzebue, Alaska

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Cancer occurs when some of the millions of cells in our bodies become damaged and grow without control and order. Cancer can develop anywhere in the body. It can develop in an organ, such as the stomach, when abnormal cells form a lump or mass. It can start in places where solid cancers don't form, such as in the blood or bone marrow.

Cancer is not just one disease, but more than 100 different diseases. Not only are there many kinds of cancer, there are many different causes of cancer. Still, all cancers have things in common. Cancer cells grow and divide rapidly, robbing nutrients from healthy cells. Normally, growth of new cells and loss of old cells is kept in balance. When a person develops cancer, this balance changes.

Cancer cells may spread to other parts of the body. The cancer is always named after the organ where it first started to grow, or the "primary site." For example, if colon cancer spreads to the liver, the cancer cells in the liver are colon cancer, not liver cancer.

Some cancers can be prevented. For instance, the best way to prevent lung cancer is to avoid smoking tobacco. For many other cancers, it is not easy to identify the cause.

Some cancers can be detected early. Screening tests can help detect some cancers at an early stage. Pap tests, mammograms and exams of the large intestine are examples of cancer screening tests. Unfortunately, there are no early detection tests for all kinds of cancer. The earlier cancer is diagnosed, the more likely it can be treated and cured.

"Alaska Natives living in remote communities are used to dealing with hardships on a daily basis just to survive in a harsh climate. They frequently face tragic events that all too often end in death. Many patients don't show a lot of emotion and many don't complain, as cancer is just one more obstacle they are facing."

"A comprehensive, integrated cancer plan for Alaska Natives is important in our fight against this devastating disease. It will provide tools to help us identify resources to help prevent and treat cancer and to use those resources wisely."

Paul Sherry
ANTHC CEO

Everyone knows someone who has been touched by cancer. A diagnosis of cancer not only affects the patient, it affects family, friends and the entire community. Cancer can drain a family's financial resources, time and energy. It can take years from the time cancer is first suspected, diagnosed, and treatment is completed. After treatment, survivorship issues require new resources and efforts. When cancer can't be cured, the loss of a respected elder, parent, child, or friend is devastating.

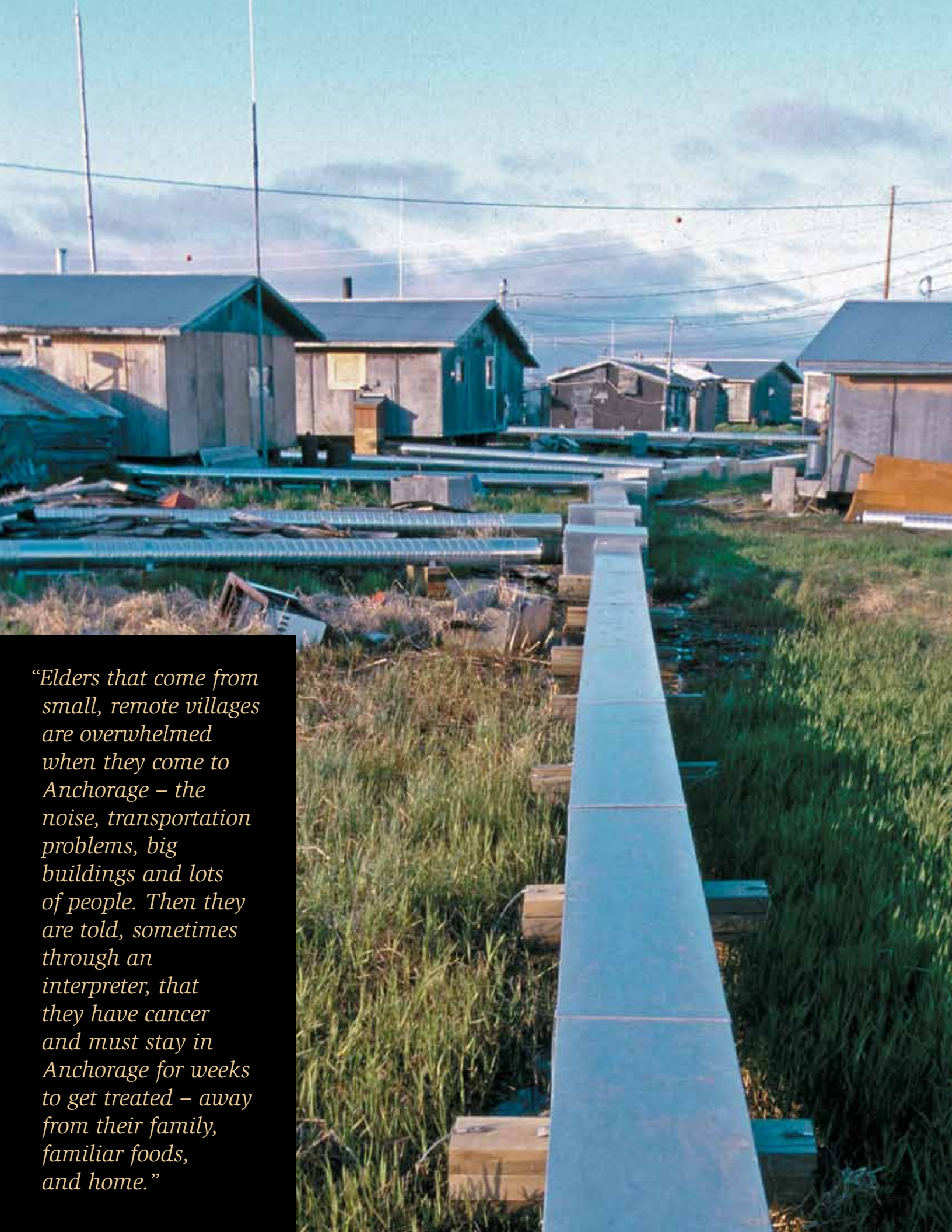
For Alaska Natives, the problems associated with a cancer diagnosis are even greater. Cancer care often means long family separations because patients living in remote communities must leave home and travel hundreds of miles for treatment in Anchorage or outside of Alaska. Only in rare situations is the family able to travel with the cancer patient during treatment. Even then, families struggle to maintain a temporary household in unfamiliar surroundings without cultural and social support. When a patient returns to a village, there are limited resources available to help care for and support the patient and family.

When cancer is suspected in Alaska Native children, they are generally referred to the Children's Hospital in Seattle for diagnosis and treatment. The child and family members travel to Seattle and remain there for several months during the course of treatment, and often return to Seattle for follow-up care. Pediatric oncologists from Children's Hospital also conduct regularly scheduled clinics at the Alaska Native Medical Center (ANMC) for follow-up care.

Cancer was not a major cause of death in Alaska Natives during the first part of the 20th century. For the most part, the main cause of death was infectious disease. In 1943, 43% of all Alaska Native deaths were due to tuberculosis. By the early 1990's, cancer was the leading cause of death.

In the United States, the overall cancer death rate declined throughout the 1990's. In contrast, Alaska Native cancer death rates increased. Alaska Native women have the highest cancer death rate of all racial and ethnic groups while Alaska Native men rank third after African American and Hawaiian men. The number of new patients diagnosed with cancer each year continues to increase. To help further the understanding of the burden of cancer on Alaska Natives, information presented here is drawn from over 30 years of cancer data from the Alaska Native Tumor Registry (ANTR) and state and national databases.

It is important to remember that cancer in Alaska Natives is more than numbers and statistics. It is about people and lives affected during the cancer journey. The following stories are about loss, hope, culture, reaching out and sharing. They tell the real story of cancer in Alaska Natives.



"Elders that come from small, remote villages are overwhelmed when they come to Anchorage – the noise, transportation problems, big buildings and lots of people. Then they are told, sometimes through an interpreter, that they have cancer and must stay in Anchorage for weeks to get treated – away from their family, familiar foods, and home."

Jesse Carter

Jesse Carter, 66 years old, is a Yup'ik Eskimo from Kquinhagak. The village is located near the Bering Sea Coast and its origins date back to 1,000 A.D. Most households in the village do not have indoor plumbing and residents must haul water from a central source. Subsistence is a large part of life in the village. Depending on the season, hunting, fishing and gathering berries and their preparation and storing is a focus of daily life. A retired fisherman, Jesse also retired in 1984 from the National Guard after 24 years of service. He and his wife Sally have four grown children and many grandchildren. Jesse was diagnosed with pancreatic cancer in 2003 and must fly to Bethel from Quinhagak and then on to Anchorage for cancer care. Sally travels with him. They have young grandchildren and Sally is torn with being away from home and wanting to be with Jesse.

Jesse: I used to hunt and fish. Now I can't. Our children give us fish and caribou. I am tired of the travel to go to the hospital and see the doctors. I get tired so easily. We have to fly to Bethel and then to Anchorage to see the oncologist. When we go home we try to make it on the same day, but we usually can't make it in one day and have to stay overnight in Bethel. Last year our electricity was cut off because we couldn't pay the bill. I can't work anymore. I like Sally to travel with me to the hospital but it is hard on her too. She didn't get to go berry picking last year.

Sally: When Jesse wasn't sick, he was very active around the village. We know everyone in the village. When we are home, Jesse is always walking around. I tell him he should rest. He walks to the post office and sometimes all the way to the clinic. He says, "If I rest too much I get weak." This winter we ran out of fuel oil and it was cold in our house. Jesse gets cold so easily now. Our telephone service was also cut off. Now we have to call from someone else's house when it is time to arrange travel for Jesse to see the doctor or when he gets sick. It is better when we can stay in quarters at ANMC when Jesse gets treated. We don't have to worry about getting food and water or the heat and electricity.

Jesse & Sally Carter

Ray Soloman Photo

"Fighting cancer is hard work. It takes a patient's physical, emotional and spiritual strength to fight this disease. When a patient lives in an isolated village that requires hard physical work several hours a day, every day just to survive, how can he fight cancer too?"

Dawn Hackney, RN, BSN
Yukon Kuskokwin Health Corporation

Ruth Nelson

Ruth Nelson, 45 years old, is an Inupiat Eskimo from Kotzebue and one of 10 children. Her mother made parkas, mukluks, and yoyos and worked on polar bear skins. Her father was an ivory carver. Both parents were Eskimo dancers and tribal leaders. She has five children and is a teacher's aide.

Ruth: In 1994 I was nursing my youngest daughter and felt a lump in my breast. I went to the doctor and she knew something was wrong. I came to Anchorage for a biopsy and was diagnosed with breast cancer. I had surgery, chemotherapy and radiation. It was really hard to be away from my family, especially my baby.

It was hard on my children too. They were so worried about me. My son said "Are you going to make it to my graduation?" When I was getting treatment, one of my sons failed a grade in school but his teacher was a breast cancer survivor, so she talked to him and helped him understand about the cancer.

When I was first diagnosed with cancer, I didn't want to talk to anyone. Then a man who had liver cancer and his wife came to see me when they heard I had cancer. He said, "I went through it, and you can too." I knew then I had to fight it.

In 1996, I went to Seattle for a stem cell transplant. I was down there for eight weeks, two different times. My husband couldn't be with me. He had to take care of our children. My sisters came to be with me for part of the time. I thought I wasn't going to make it through the stem cell transplant, but I did. Afterwards, two of my sisters were diagnosed with cancer--thyroid cancer and colon cancer. We supported each other.

We have a really good support group in Kotzebue. When someone is diagnosed with cancer, the nurse at the hospital will ask the patient if she can contact us to provide support. I get calls from people

Carmelita Nattanguk

Carmelita Nattanguk, 52 years old, is an Inupiaq Eskimo from King Island. She was a "summer baby," born in Nome when her parents came to sell the carvings and hand-sewn items they made during the winter months. The family moved to Nome when Carmelita was seven years old because the Bureau of Indian Affairs no longer sent teachers to King Island. They returned each summer to King Island to hunt, gather bird eggs, and pick berries and greens to take back to Nome for the winter. King Islanders are known for their exceptional ivory carvings and crafts, as well as Eskimo dancing.

Carmelita: I met David in Nome when I was 16 years old. He was from King Island, but I didn't know him. He wanted to marry me, but my mother told him to wait until I graduated. We were married in 1971 and had five children. David was well known for his ivory polar bear carvings that he sold statewide.

In 1999, the Ear, Nose and Throat (ENT) doctor came from Anchorage to hold a specialty clinic at the Nome hospital. I made an appointment for David. He took x-rays and saw a tumor. David had to go to Anchorage for a biopsy. He called me to tell me he had nasopharyngeal cancer. In 2001, the cancer spread to his liver.

I quit my job to take care of him and be with him. We had to use my retirement savings. We traveled to Anchorage for chemotherapy and radiation and stayed with family, but it was hard to keep taking the bus and cabs to the hospital for his treatment when he was so tired. It was better when we moved to quarters at ANMC. The staff at the ANMC Oncology Clinic was wonderful and helped us, but David was always happy to be going home after treatment. He was the first one to pack when he knew he was going home. It was really hard to be away from our family and friends.

There was a nurse, Theresa, at the hospital in Nome. She was always there to help us. She knew how to give chemotherapy and provide support to us so David could stay in Nome. But she left and it was very hard on us.

Sometimes David felt better after getting a blood transfusion. He always carved ivory when he felt better. Towards the end he couldn't carve any more. During his last few days, he kept falling when he tried to go to the bathroom. My son Jeffrey and I picked him up and put him back in bed. My son Butch and I were with him and holding him at the time of his passing. He went peacefully.

I thought he was going to be okay after the chemo and radiation. I didn't know

"We really need programs to help cancer patients stay home when they are not going to get better. We need help with pain and symptom management and knowing how to care for our loved ones. We need help for families dealing with grief when someone is dying from diseases like cancer."

Carmelita Nattanguk

who know I am a cancer survivor. I like to help others when they are diagnosed with cancer. I know how hard it is to hear those words—"you have cancer."

When someone in Kotzebue is diagnosed with cancer, we start fund raising. We open a bank account for the family, have bake sales and other events and put donation canisters around town. We know cancer patients can't get cancer treatment in Kotzebue and it is expensive for the patient and family to go to Anchorage. We share what we have, just like our people always have done. Even now, we still trade food between villages--muktuk for caribou, shee fish for seal oil.

At home we are trying to change the way we eat and are eating more traditional foods. We try not to eat so much Western food even though we really like it. My favorite traditional food is shee fish, which we go out on the ice to catch. My husband hunts for birds, seals and caribou. We go to fish camp in the summer and get white fish and seal meat and hang it to dry so we have it for the winter.

I have survived my cancer for over eight years--a long time. I am glad I went to the doctor as soon as I found a lump in my breast. Early detection is important. If you feel a lump or someone in your family has cancer, make sure you check it out. Don't wait too long to get checked. Don't be scared. Be strong. Find someone to talk to who understands. Don't give up on your treatment. You can make it, just like I did.

Ruth Nelson & Carmelita Nattanguk

his cancer could spread. I didn't know anything about cancer and tried to find out anything I could. I wish he had never gotten sick. He died too young. People say, "You are such a strong woman." I didn't know that. I just knew I had to take care of him. Every day I said, "I love you" to him.

We really need programs to help cancer patients stay home when they are not going to get better. We need help with pain and symptom management and knowing how to care for our loved ones. We need help for families dealing with grief when someone is dying from diseases like cancer.

I still miss David. I miss his touch. He was a strong man, very loving, very proud of our children and grandchildren. Just after he passed away, I could feel him against my back when I was in my bed. When I had surgery, he was with me. I don't feel him any more. I know he passed over. But when our two-year-old grandson died in February, I know David came back and took his hand to take him with him.

David Nattanguk passed away on Sunday, September 1, 2002.

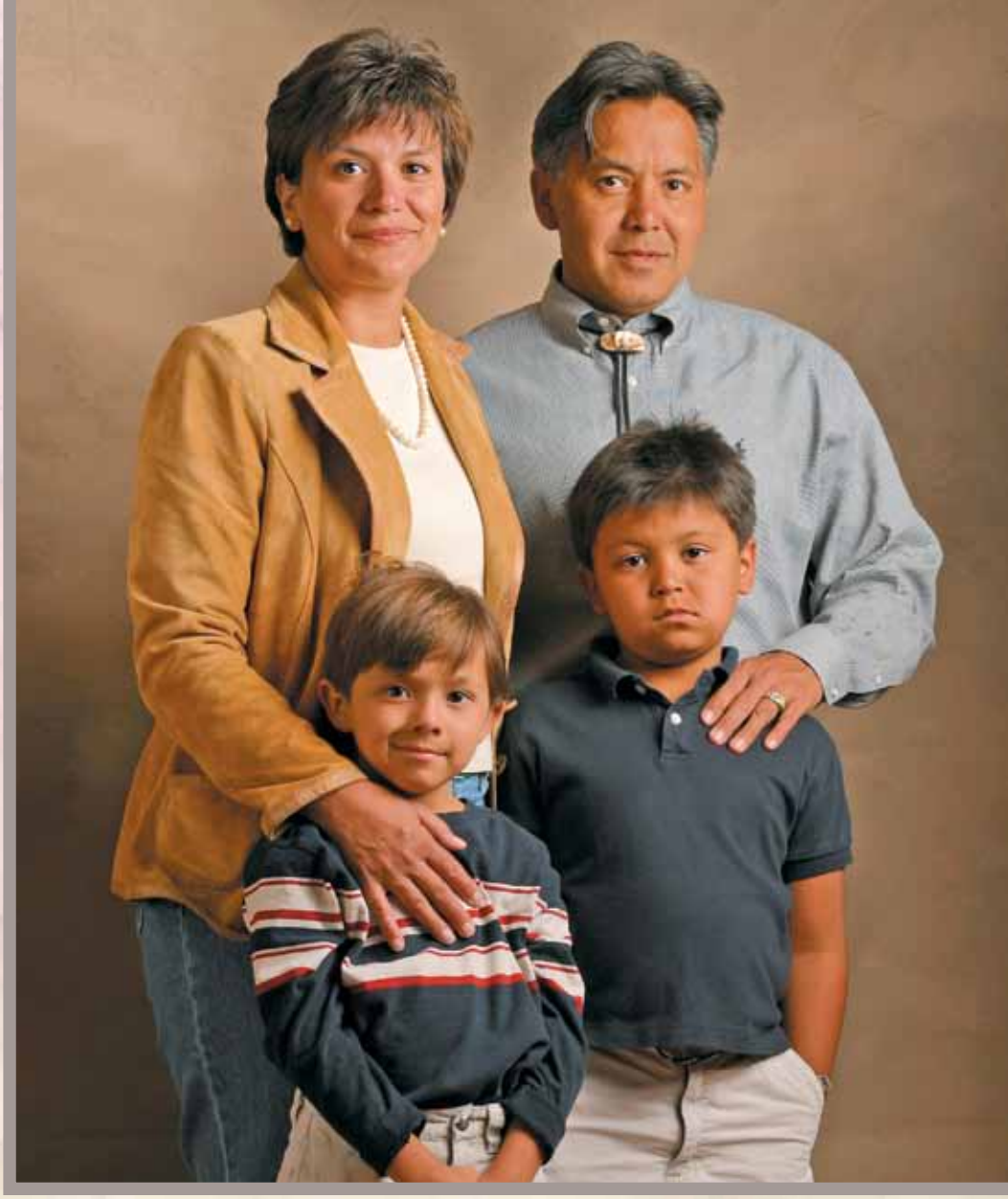
Tim Gilbert

Tim Gilbert, 46 years old, is an Inupiaq and Tsimshian. His family is from Kotzebue and Metlakatla. When he was five years old, he was diagnosed with fibrosarcoma, a rare cancer that affects fibrous tissue. He was successfully treated at a Seattle, Washington hospital.

Tim: I was adopted as an infant and grew up in Washington State with my adoptive parents and sister who was also adopted. As a young adult, I wanted to know more about my biological family and began to search for information. I learned that my father's family lived in northwest Alaska. I traveled to Kotzebue and began to learn and experience my Alaska Native heritage. In 1998, a job became available as hospital director for the Maniilaq Association in Kotzebue. The opportunity to live in the same village as my father's family was overwhelming—it was a chance to be close to them and a lifestyle that I had never experienced.

Getting to know my grandparents, Levi and Annie Mills, was very important to me. My grandfather was respected as a subsistence hunter and fisherman and a founder of Kotzebue. At the time, he was in his nineties and very frail. As a hospital administrator I had a front row seat watching how difficult it is for an elder to be medevaced to Anchorage for care and then back again to Kotzebue where he passed away. I felt a great loss when he passed.

My father was also a subsistence hunter and fisherman. He felt it was important to catch me up on the skills I didn't know—navigating waterways and learning to hunt and care for caribou. He taught me skills that I missed while growing up in an urban setting. I learned the difference between sport hunting and subsistence hunting and how important hunting is to survival in northwest Alaska.



Alisa & Tim Gilbert with sons Race & Levi

I don't remember much about having cancer as a young child. I remember having a lump near my knee, being in the hospital a lot, and eventually having a cast on my leg. I had surgery and chemotherapy but have not experienced long-term side effects from the disease.

As an adult, my interest in cancer started when I was in graduate school working in public health and epidemiology. I remember reading Dr. Anne Lanier's publications on cancer in Alaska Natives. After completing my Master's degree in public health, I worked with American Indian and Alaska Native cancer projects in New Mexico and the Pacific Northwest. I also worked as a research associate while at the Fred Hutchinson Cancer Research Center in Seattle.

I met my wife, Alisa, in Seattle in 1995. She was recovering from breast cancer treatment and waiting for reconstructive surgery. Suddenly my interest in cancer was no longer academic or a vague memory of having cancer as a child. I had to take "book learning" to a personal level. When Alisa became pregnant with our first son Levi, we pored over literature about the impact of pregnancy on the recurrence of breast cancer. It was important for us to understand the risks to Alisa's health.

Race was born two years after Levi. Now we celebrate and appreciate life as a healthy family.

Markle Ewan

Markle Ewan, 58 years old, is an Athabaskan Indian from Gulkana, on the east bank of the Gulkana River at its confluence with the Copper River. He worked in the construction industry most of his life and is now retired, living in Anchorage. He spoke his Native tongue until he was six years old when he went to school and was required to speak English.

Markle: Growing up, I thought everyone was born under a rock on the East Fork of the Gulkana River. When people tell me I'm crabby, I say, if you were born under a rock in July when it was minus 40 degrees, you would be crabby too!

When I was growing up, there was no such thing as cancer. Even if you had cancer, no one knew what it was. Everyone died of "natural causes." There is no word for "cancer" in our language. Now there seems to be so much cancer everywhere including the Copper River area. My mother, mother-in-law, grandaunts and sister died from cancer. And now I have lung cancer.

How can you tell what causes cancer? Is it contaminants in the fish, caribou, berries and roots we eat? I smoked for 45 years, but I also worked in the construction industry and was exposed to asbestos. There are so many questions. You could study it for 25 years and still not know what caused cancer.

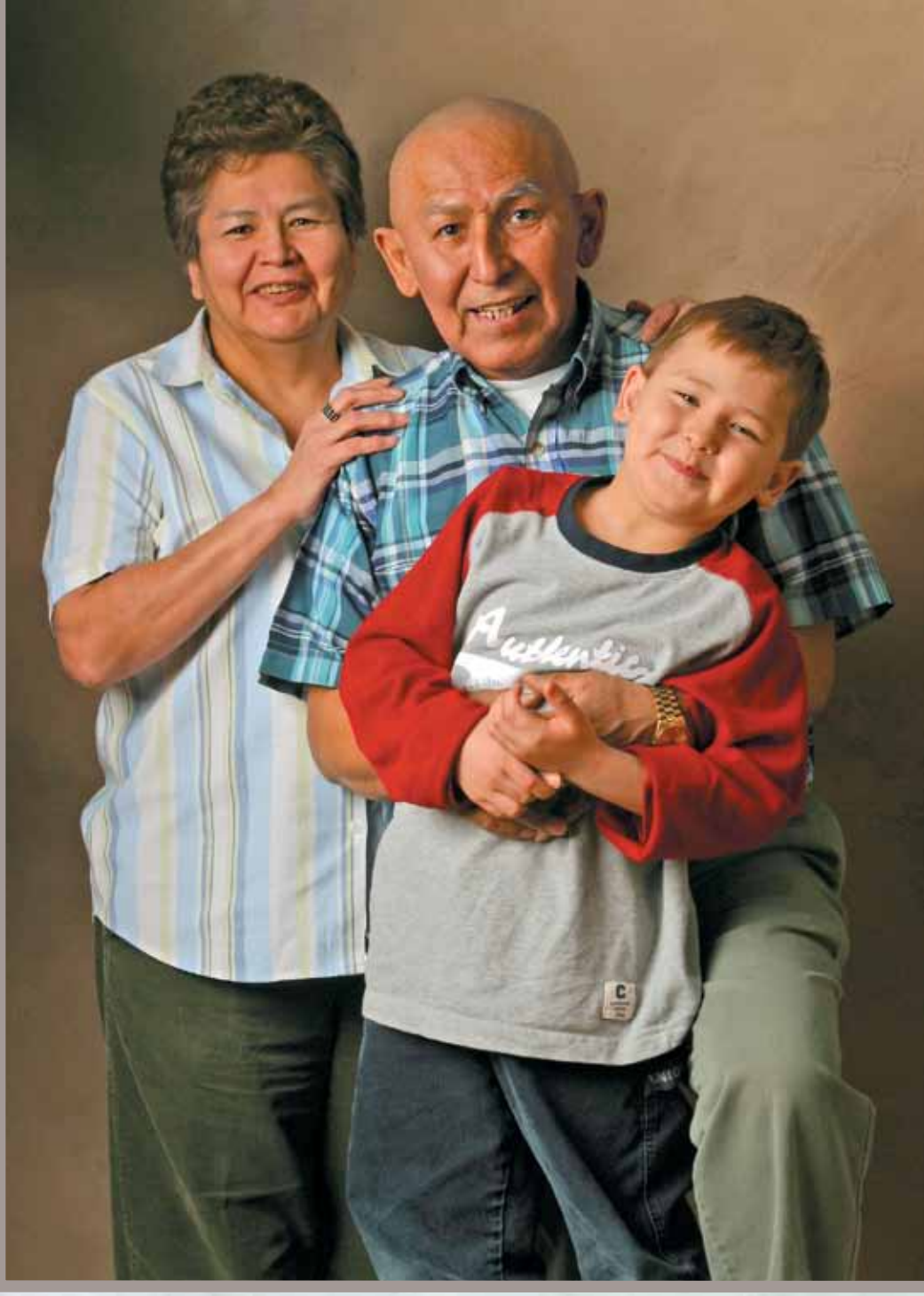
My cancer was discovered when I got a chest x-ray for pneumonia. The x-ray technician found a spot on my lung and a biopsy showed it was cancer. I have had radiation and chemotherapy. I was healthy and very active before I got cancer. I think that helped me get through treatment.

When I found out I had lung cancer, it was a shock. It traumatized not only me, but my whole family. We had a dinner and invited our family and friends and told them I had cancer. My wife has really been supportive. It is important for people to have the support of family and friends, especially when you first learn you have cancer. Getting chemotherapy and radiation is hard and the side effects can be bad. I think some people don't understand the pain and trauma that comes along with the cure and some people aren't prepared to fight the disease.

I am lucky because a lot of my family is here in Anchorage. People in the villages don't want to leave their families for long periods of time. They need family support especially when they are getting treatment, but travel is expensive.

When you have cancer you never know how you are going to feel. I wanted to take my wife out to dinner for her birthday. I felt okay in the morning, but didn't feel good later and we couldn't go to dinner. Then it was our 33rd anniversary and we went out to dinner, but I could only eat a few bites.

My grandson, Tyler, is my joy. He keeps me going.



Margie & Markle Ewan with grandson Tyler

Frances Lampe

Frances Lampe, 64 years old, is an Inupiat Eskimo living in Kaktovik in the Arctic National Wildlife Refuge on the Beaufort Sea. The wife of a whaling captain, Frances raised six children now 12 to 40 years old. She is a generous woman and good cook. Everyone loves her "Eskimo donuts."

September brings whaling season to Kaktovik, a village-wide activity. Women prepare food to send out with the whaling crews and wait on the beach for the crews to return with a whale. The day after the whale is beached, everyone goes to the captain's house to eat whale meat and muktuk. They spend the whole day visiting and eating and then take some of the leftover whale meat home with them. Each summer the extended family travels to nearby Griffin Point, Frances' birthplace, to fish. Four generations have made the annual trip. Frances was diagnosed with ovarian cancer in 2000.

Frances Lampe & niece Marie Rexford

Frances: My family is so important to me. We inherited our beliefs from my parents. They taught us it is important to be generous with others and always share our food, even if we have only a little.

When I was diagnosed with cancer, I had to go to Seattle for surgery. It was very scary for my family. My husband and my children came to Seattle with me. I stayed in Seattle for two months and was in a coma for part of the time. When my family had to go home, Flossie had a big photograph of everyone taken and hung it in my hospital room so I could see it. I love pictures.

Flossie: As soon as Mom woke up from her coma, she said "What do I have to do to go home?" She was so weak. But she was determined. She would lie in bed and do leg raises and make us count for her. If we forgot, she said, "Why aren't you counting?" She came home on her birthday, April 15. When we helped her off the airplane, she put her feet on the ground and tears came down her cheeks. "I never thought I would come home again," she said. Everyone wanted to see her, but it was too cold to stay outside, so we had a big sing along at home.

Frances: When I started chemotherapy at ANMC, my older sister used to come down with me. Now she is getting too old to travel so much and my niece Marie or Flossie comes with me. The travel costs and the long way we have to fly is the hardest part of having cancer.

Frances and daughter Flossie Swanson show off her hand-knitted cap, donated by the Anchorage Weavers and Spinners Guild.

Flossie: When Mom's hair started to fall out, everyone was upset. But she said, "It's just hair, it will grow back. At least I am still here." She never complains. It costs about $2,000 for Mom and an escort to fly to Anchorage for her doctor's appointments. She can't come alone. We have had some help with donated or discounted airplane tickets. But sometimes it is only the day before her appointment when we know she will have a ticket. She is so afraid of being a burden to her family. It causes her lots of stress. She is never a burden. I tell her she has to go to the doctor and we will find a way.

She has to see the doctor again next month. I guess I will start today to try to get some help for her ticket.

Alaska Native Cancer Facts

The vast, geographically diverse land of Alaska has been home to Alaska Natives for thousands of years. Many Alaska Natives live in remote communities, accessible only by aircraft or boat. They practice many of the subsistence lifestyle activities – hunting, fishing and gathering – that have sustained Alaska Natives for hundreds of years.

Knowledge about the historical incidence of cancer in Alaska Natives is fragmentary, largely because cancer was not a major cause of death in Alaska Natives during the first part of the 20th century. The main cause of death was infectious disease. The 1954 Parran Report[1] was the first official report to describe the health status of Alaska Natives. It reported that in 1943, 43% of all Alaska Native deaths were due to tuberculosis. A report of cancer death among Alaska Natives for 1960-69 showed slightly lower rates than U.S. Whites.[2]

In 1969, Robert Fortuine, MD, MPH[3] noted that cancer was becoming a significant health problem in Southwestern Alaska, even though the true extent of the disease was probably underestimated. Early diagnosis was unusual because of the difficulty in accessing healthcare services in an area with many geographic and transportation barriers. Fortuine believed that because the population was aging, largely as a result of the marked decline in infectious disease deaths, cancer would become a greater health problem.

Cancer is now the leading cause of death for Alaska Natives.

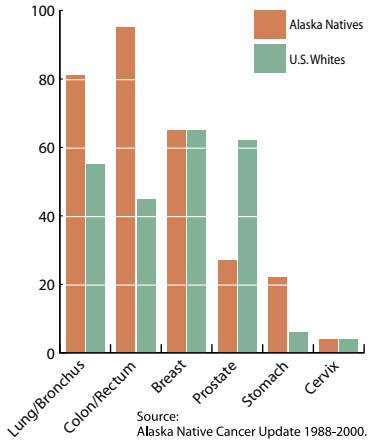
"We can't assume the incidence of cancer in Alaska Natives is the same as in the U.S. general population. In fact, it isn't. It also is not the same as in other American Indian tribes."

Anne P. Lanier, MD, MPH

INCIDENCE OF CANCER

Cancer incidence (new patients diagnosed each year) for all Alaska Natives were first gathered in 1976. The most important finding was that the overall cancer incident rate among Alaska Natives was slightly lower than in U.S. Whites. It also showed that for certain cancers, rates were several times higher than in U.S. Whites. For instance, Alaska Native rates were higher for cancers of the nasopharynx, stomach, liver, gallbladder, cervix and kidney, and lower for prostate, breast, uterus, bladder, brain cancers as well as leukemia and lymphoma.

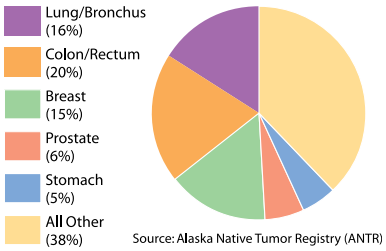
Alaska Native vs U.S. White Cancer Rates 1998-2000[4]
Per 100,000 population



Source: Alaska Native Cancer Update 1988-2000.

Data from the Alaska Native Tumor Registry (ANTR) show that cancer patterns in Alaska Natives differ from those of Whites and Blacks and other minority populations in the United States. Cancer rates among Alaska Natives also differ from those of American Indians of New Mexico/Arizona.

Alaska Native Cancer 1998-2002
Percent of All New Cases



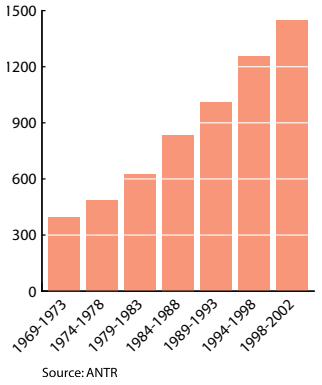
Source: Alaska Native Tumor Registry (ANTR)

The rate of new cancers diagnosed each year is, on average,[5] 7% higher for Alaska Natives (446/100,000 population) than for U.S. Whites (407/100,000). Rates for Alaska Native males are similar to U.S. males while rates for Alaska Native females are 18% higher.

For the years 1998-2002, the five most frequently diagnosed cancers were lung, colon/rectum, breast, prostate and stomach. For males, the leading cancer sites are lung, colon/rectum and prostate. Among women, breast cancer is the leading cancer followed by colon/rectum and lung.

The rate of new cancer patients diagnosed each year increased 37% from 1969-1998.[6] About 300 Alaska Natives are diagnosed with cancer each year.

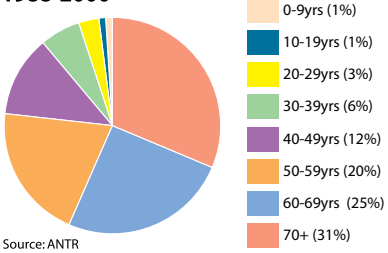
Alaska Native Cancer Cases



Source: ANTR

Life expectancy for Alaska Natives still lags behind other racial and ethnic groups. However, it has increased dramatically since 1950 when it was 47 years. Most cancers are diagnosed in older people. In Alaska Natives, 88% of cancers are diagnosed in patients 40 years of age and older. Aging of the population and increase in life expectancy contribute, in part, to the increase in the number of new cancer patients.[7]

Alaska Native Cancer by Age 1988-2000



Source: ANTR

CHILDHOOD CANCER

Compared with adult cancers, childhood cancers are rare. In the United States they make up about one percent of all cancers. From 1969-1996, a total of 131 cases of cancer were diagnosed in Alaska Natives less than 20 years of age. Cancer in Alaska Native children, as in children in other parts of the United States, is most frequently diagnosed within the first year of life. Incidence rates for specific cancers in Alaska Native children are similar to those of U.S. Whites and non-Native Alaska children. The cancer rate in Alaska Native children does not appear to be increasing. The death rate for cancer in Alaska Native children is slightly lower than for U.S. Whites.[8]

The Alaska state hepatitis B virus (HBV) immunization program began in late 1982. No child born in Alaska since HBV immunization became available has been diagnosed with hepatocellular cancer, a cancer diagnosed in Alaska Native children prior to the availability of HBV immunization.

When cancer is suspected in Alaska Native children, they are generally referred to Children's Hospital in Seattle for diagnosis and treatment. Follow-up care, including some chemotherapy is provided at ANMC in the pediatrics unit. A pediatric oncologist from Children's Hospital conducts a regularly scheduled clinic at ANMC.

When an Alaska child is diagnosed with cancer, the child and parents spend several months away from home during treatment. This creates a financial burden on the family. In addition, the family is away from their home, extended family and familiar surroundings.

ALASKA NATIVE TUMOR REGISTRY

The Alaska Native Tumor Registry (ANTR) was established in 1974 and contains cancer information about newly diagnosed patients from 1969 to the present. Information on stage at diagnosis, treatment, and follow-up care was added to the registry in 1984. The ANTR follows national standards and guidelines.[9] Agreements with state and national registries help make certain that all Alaska Native cancer patients diagnosed with cancer while living in Alaska are included in the Registry.

The ANTR tracks changes in cancer rates, as well as diagnosis, treatment and survival rates. It provides information on trends and helps identify areas needing intervention and research. The registry provides factual, comparative information to support requests for funding from government and private sources. It serves as an information base to compare cancer patterns in Alaska Natives to other populations.

"The ANTR is the best tool we have to show how cancer seriously impacts Alaska Natives. It allows us to track cancer patterns and trends as well as making comparisons with other populations. The registry is an important part of the cancer program. Most importantly, it helps us provide better patient care."

Greg Marino, DO, ANMC Oncologist

CANCER SURVIVAL[10]

Calculations of cancer survival show that among Alaska Native patients diagnosed with cancer, less than half (37%) will be alive five years after diagnosis. A larger percent of women (45%) than men (32%) will survive five years. The survival rate is improving. For patients diagnosed with cancer from 1984 to 1998, the five-year survival rate is six percent higher than for those diagnosed from 1969 to1983.

The five-year survival rate for some cancers improved significantly (colorectal 20%, Liver 42%). For all population groups, the likelihood of surviving five years varies by the cancer site. Nearly all patients diagnosed with cancer of the thyroid, testis, and uterus were alive five years after diagnosis, while none of those with cancers of the esophagus or pancreas survived five years. In addition to cancer site, the extent to which the disease has spread (stage) at the time of diagnosis also determines length of survival.

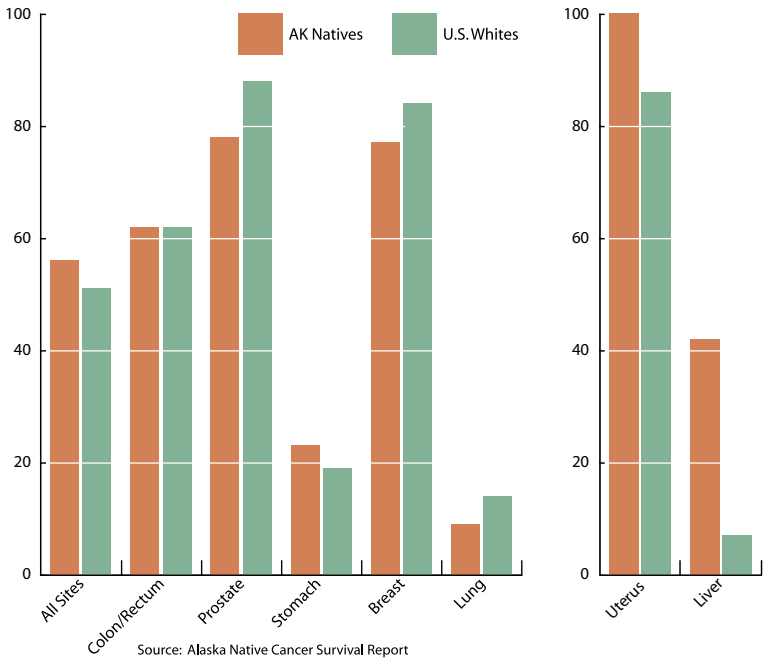
Cancer Stages

LOCAL	Cells haven't gone beyond the original site, for example, the breast.
REGIONAL	Cells have gone beyond the original site, but not beyond the surrounding lymph nodes and adjacent tissue.
DISTANT	Cells have spread extensively in the body.

Between 1984-1994, less than 40% of all cancers in Alaska Natives were diagnosed at the local stage. Overall, Alaska Natives had a higher proportion of cancers diagnosed at later stages than U.S. Whites between 1984-1994. When cancer in Alaska Natives and U.S. Whites is diagnosed at the same stage, five-year survival rates are similar.

Comparison of Alaska Native and U.S. White five-year survival rates (1984-1994) show that for all cancers combined, Alaska Natives have an 11 percent lower five-year survival rate. Differences in survival rates between Alaska Natives and U.S. Whites are due, in part, to the types of cancer that occur more frequently in Alaska Natives. Many cancers with poor survival rates occur more often in Alaska Natives. Cancers of the esophagus, pancreas, lung, gall bladder and nasopharynx have poor survival rates in all populations and account for a greater percentage of cancers diagnosed in Alaska Natives. For breast, stomach, prostate and cervical cancer, Alaska Native survival rates are similar to U.S. Whites. For two sites, liver and uterus, Alaska Natives are more likely than U.S. Whites to survive five years.

Percent of Cancer Patients Surviving 5 Years[11]

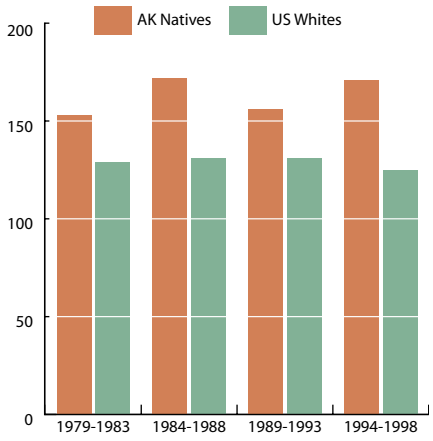


Source: Alaska Native Cancer Survival Report

CANCER DEATHS

The death rate for all cancer sites is higher for Alaska Natives than for all Alaskans (1991-98)[12]. In 1999, the cancer death rate was 238/100,000 for Alaska Natives and 193/100,000 for all Alaskans.[13] Although overall U.S. cancer death rates declined throughout the 1990s, Alaska Native cancer death rates increased.

Cancer Death Rates in Alaska Natives & US Whites



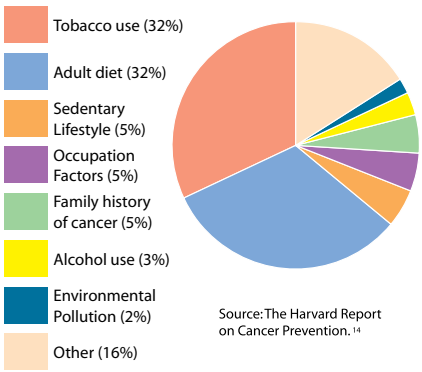
Source: Alaska Native Mortality Report

In the five-year period, 1994-1998, Alaska Native death rates from cancer were 30 percent higher than for U.S. Whites. For the period 1989-92, rates among Alaska Native women were the highest of any racial/ethnic group in the U.S., while Alaska Native men rank third after African American and Hawaiian men.

CAUSES OF CANCER

Some causes of cancer are well documented. For instance, smoking tobacco is the number one cause of lung cancer. Unfortunately, we don't know what causes many cancers. We know that by reducing exposure to cancer-causing agents such as tobacco, and by promoting healthy nutrition and physical activity practices we can reduce the risk of developing some cancers. Prevention of tobacco use among children and youth is critical. More than 80 percent of smokers begin to smoke before the age of 18 years. Subsistence foods in general are much healthier than store-bought foods. In addition, hunting, fishing and gathering berries and greens require an increase in physical activity.

Causes of Cancer in Alaska Natives



Source: The Harvard Report on Cancer Prevention.[14]

RISK FACTORS

A risk factor is anything that increases a person's chance of developing a disease. Some cancer risk factors can be controlled such as smoking, eating habits and exercising. Some risk factors can't be controlled such as age, and family history of cancer. Some people with several risk factors never develop cancer, while others with no known risk factors do develop cancer.

"Alaska Natives are 40% more likely to die of lung cancer than U.S. Whites. They also have higher death rates for several other smoking related cancers like kidney, bladder, head and neck, and cervix.[15] Eliminating tobacco use would substantially impact the Alaska Native cancer death rate."

Anne P. Lanier, MD, MPH

"Contacting patients and getting them to Anchorage for follow-up care is hard. In some areas, two-way radio is the only communication tool. Patients living in remote areas may not be able to get to Anchorage for weeks—muddy runways, rivers full of ice, no snow—can stop them from traveling. When you live in an area without roads, you are dependent on other means of transportation and the use of snow machines, boats and small airplanes is 100% weather dependent."

VILLAGE CANCER CARE

Community Health Aides/ Practitioners (CHA/P) are the backbone of the Alaska tribal health system. CHA/Ps are village residents who provide primary healthcare services in remote villages. They work under direction from physicians located at regional hospitals and ANMC. Cancer care is not part of the standard CHA/P curriculum. Some CHA/Ps have completed a course in cancer education, but it is still difficult to know what to do with limited resources, especially when the cancer patient is a family member.

"I've dealt with cancer in my family and as a CHP. At times I feel pretty helpless and frustrated. When it is your family, you forget all you know. My mom was a CHA for years, but now that my dad has cancer, she needs direction. As a daughter and a CHP, I sometimes get confused about my role.

When you know a patient is dying, you try hard to help them. You don't want them to be in pain but sometimes you get different information about what to do. The family is very upset and looks to us for support. We try to support them the best we can, but sometimes we don't get enough information or patients come home with equipment that we don't know how to operate. We need more training."

Sue Anelon,
Community Health Aide Program (CHAP)
Field Coordinator, BBAHC

"Cancer patients don't want to stay in Anchorage and they don't want to stay in Kotzebue. They want to be home in their village with family and friends."

Rob Reeg, MD, Maniilaq Association, Kotzebue

"Alaska Natives have one of the highest rates of colon cancer in the world but early detection and treatment can cure this cancer. Our challenge is to raise our patients' awareness of the importance of screening and to provide access to screening services."

Frank Sacco, ANMC Surgeon

SCREENING/EARLY DETECTION

While it is not possible to prevent all cancers, detecting cancer early before it spreads to other parts of the body increases the chances for survival. There are proven tests that help detect cancer at the earliest possible stage for cervical, breast, and colorectal cancer. A screening test for prostate cancer is still being studied to determine effectiveness.

An example of the effectiveness of an early detection/screening program is the significant reduction in cervical cancer in Alaska Natives. Widespread screening for cervical cancer through the Pap test is credited with significantly reducing the incidence of cervical cancer and diagnosing it at an early stage.

Mammograms can detect breast cancer at an early stage. Mammography services are available in Anchorage and the regional hospitals. Even though travel is expensive for women living in remote communities, they are encouraged to get annual mammograms as recommended.

Colon cancer screening resources are only available in Alaska's major cities and some regional hospitals. The lack of trained healthcare providers and equipment limits the extent of screening programs. Like access to all health care services, access to colorectal screening is limited not just by availability of equipment and personnel, but by the high cost of transportation. Since colorectal cancer is one of the top three cancers in Alaska Natives, expanding the availability of screening is important.

DIAGNOSING CANCER

From the time cancer is suspected in an Alaska Native patient, it may take several weeks before cancer can be confirmed or ruled out. Weather, transportation problems, access to specialists and equipment, time of the year, and other factors may lengthen the time before a cancer diagnosis is confirmed. Most Alaska Natives must travel to Anchorage for diagnostic mammograms, CTs, MRIs and other tests. They may have to stay in Anchorage for several days to complete tests, which may be scheduled at different locations around Anchorage. A tissue sample (biopsy) is needed to confirm a cancer diagnosis. Several biopsies may be needed before a diagnosis is confirmed. For some cancers, biopsies may be done at the regional hospital and tissue sent to the ANMC Pathology Department. However, in most instances, patients travel to Anchorage for biopsies. For patients and their families, navigating the medical system when cancer is suspected is often a confusing process.

Once cancer has been confirmed, the patient's case is presented to the ANMC Tumor Board. Information about the patient's case, including pathology slides and radiographic studies, is reviewed and discussed by pathologists, radiologists, surgeons, oncologists, internists and other specialists who attend the weekly meetings. The best course of treatment is then recommended. The patient's physician shares this information with the patient.

TREATING CANCER

Cancer treatment takes more than the patient and one doctor. It takes a multidisciplinary team approach that may include the patient, family, physician specialists, nurses, nutritionists, social workers, Community Health Aides/Practitioners (CHA/P), and many others.

Cancer treatment generally includes one or a combination of therapies: surgery, radiation therapy, chemotherapy, immunotherapy and hormonal therapy. The patient's physician, with consultation from other physicians, recommends a treatment plan based on the type of cancer, the extent of the cancer, the patient's overall physical health and recommended treatment protocols based on international standards of care.

Most Alaska Natives receive cancer treatment at ANMC. Patients living outside the Anchorage area must fly to Anchorage for treatment and may remain in the city for several weeks depending on the type of treatment they receive and treatment side effects.

For some cancers, only surgery is needed. For others, radiation therapy and/or chemotherapy is needed. Depending on the patient's cancer, a combination of therapies may increase survival. ANMC contracts for radiation oncology services since they are not available at ANMC. In Alaska, radiation therapy is available only in Anchorage and Fairbanks. Patients must travel between ANMC and another Anchorage hospital if both radiation therapy and chemotherapy are needed. This is especially difficult for patients who live outside of Anchorage as they must take a bus or taxicab to different treatment locations.

Experienced general and sub-specialty surgeons at ANMC provide surgery and follow-up care to cancer patients. There is only one oncologist in the Alaska tribal health system to meet the needs of newly diagnosed cancer patients as well as provide care for patients undergoing treatment. The oncologist and surgical staff provide consultative support to physicians at the six Alaska Native regional hospitals in Sitka, Dillingham, Bethel, Nome, Kotzebue and Barrow before and after patients return home.

Chemotherapy is provided at ANMC in the outpatient clinic. Some chemotherapy services are available at regional tribal hospitals with the treatment plan established through ANMC or other cancer programs. Often, there is only one nurse trained to give chemotherapy at a regional hospital. If that nurse leaves (and the turnover rate of healthcare professionals working in remote hospitals is high), patients must travel to ANMC for chemotherapy until another nurse is trained.

Treatment for cancer changes rapidly. Cancer research findings, new drugs and clinical trial results provide new ways to treat patients, reduce side effects and increase survival rates. Advances in surgery have resulted in less invasive surgery including smaller incisions, and shorter recovery time. For some cancers, radiation therapy times can be shortened.

"When a patient arrives in Anchorage, finding a safe and quiet place is hard. When Quyana House (patient quarters) is full, patients must stay elsewhere, often at low cost hotels. Daily travel for tests and treatment increases their burden. Cancer treatment is hard on patients, both physically and mentally. Being able to get the right amount of rest is important."

Christina Morrison, RN ANMC Oncology Clinic Manager

"For Alaska Natives, seasonal activities are critical to survival. Personal health is a secondary consideration. Many Native patients agonize over the decision whether to receive cancer treatment at the best time or delay it so they can take part in subsistence fishing. I completely understand their dilemma, but I wish it were a choice they didn't have to make."

John Kokesh, MD
ANMC ENT Physician

"How do you pay your bills and feed your family when your whole year's income is primarily based on what you make fishing during the summer and you have just been told you need to stay in Anchorage for cancer treatment?"

Barbara Abair,
RN, ANMC ENT Case Manager

ALASKA NATIVE CANCER CARE

All cancer patients make changes in their day-to-day lives when they hear the words, "You have cancer." Alaska Native cancer patients make these same changes, but face major access to care issues as well. They must stay in Anchorage or other cities for tests and treatment, often hundreds of miles away from family, friends and their traditional lifestyle.

Summer and fall is a very important and busy time for Alaska Natives. It is the time when they hunt, fish and gather the berries and greens that make up a large part of their diet and sustain families through the long winter months. It is hard to be away from home during this time—for any reason. Cancer treatment and its side effects often reduce an Alaska Native's chance to hunt or fish during the short season.

Access to cancer care is expensive and difficult. Over 80 percent of Alaska Native cancer patients receive some form of cancer care at ANMC in Anchorage. Patients must fly to ANMC if they don't live in the Anchorage area. Some patients may qualify for Medicaid, which pays for travel for medical appointments. Some Native health corporations pay the cost of travel for patients not covered by Medicaid, others don't.

Alaska Natives are three times as likely as other Alaskans to be poor. Half of Native families live below the poverty level. The remote areas where incomes are the lowest are also the places where the cost of living is highest. While Alaska Native employment opportunities are increasing, only 35 percent of Alaska Natives have full time, year round jobs.[16] As more Natives gain employment, they often don't qualify for Medicaid or other support and yet don't make enough money to pay for numerous trips to Anchorage for cancer care. They have joined the ranks of thousands of Americans as the "working poor."

"Even though he was not finished with his chemotherapy, a patient wanted his mediport removed. The mediport is used to administer chemotherapy, so I asked why he wanted it removed. He told me it was hunting season, and his rifle butt rested on the mediport making it impossible to shoot. Now we ask our patients if they hunt right- or left-handed before placing mediports." *Greg Marino, DO, ANMC Oncologist*

SURVIVING CANCER

When cancer treatment ends, people often expect life to return to the way it was before they were diagnosed. This rarely happens. Cancer disrupts lives. A family's financial resources may be exhausted. The cancer patient may not be able to return to work, and may experience changes in self-image. Relationships with family and friends may change. There may be new health problems caused by the disease or treatment.

Ongoing follow-up care is needed to help determine if there are other types of cancer present, if cancer has recurred, and to monitor treatment side effects. Follow-up care can include home care, pain management, physical or occupational therapy, and emotional and mental health support. As the number of people who survive cancer for longer periods of time increases, more attention must be directed to identifying the needs of cancer survivors.

Follow-up care for Alaska Native cancer survivor patients living in remote areas is often difficult. Most small villages have limited health care resources and village-based workers lack training to meet the additional needs of cancer patients. One of the best support resources in the community is other cancer survivors. They generously reach out to newly diagnosed cancer patients as well as to those returning to the community after completing treatment.

PALLIATIVE CARE

Palliative care means taking care of the whole person, body, mind and spirit. It addresses care needs of people with serious life-limiting illnesses such as cancer. Palliative care focuses on bringing comfort to the patient even when cure may not be possible. It offers emotional and spiritual support to the patient and family while respecting culture and traditions. While it is often equated with patients nearing the end-of-life, in reality, a patient with a serious illness may need palliative care for a long time. Hospice programs provide palliative care to people nearing the end-of-life.

End-of-life programs that provide an option for terminally ill patients to die at home or close to home are available in most communities throughout the Uunited States. Alaska Natives who live in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. Alaska Natives living in large cities can access hospice programs. However, those living in remote communities do not have palliative care or hospice services available. The Bristol Bay Area Health Corporation (BBAHC) in southwest Alaska is the only region that has a palliative care program. Even that program has severely limited resources, with only one nurse trained in palliative care available for residents of villages located throughout the 46,000 square mile service area.

Just as cancer treatment requires a team of people, palliative care requires a team. Whether it is hospital staff or village healthcare providers, special training in palliative care helps the patient, family and healthcare providers better understand and address a patient's needs.

Healthcare providers of Alaska Natives throughout the Alaska Native healthcare system recognize the need for palliative care training. A system-wide training program is needed to help make certain that cancer patients in need of palliative care have resources available to them in their home community, at a regional level, and at ANMC.

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SUMMARY

Unfortunately, cancer will continue to be a leading cause of death for Alaska Natives for many years. However, we are not helpless in the battle against cancer. Focusing our efforts on preventing cancer through healthy lifestyle choices is important in our fight against this disease. We know there is a direct link between smoking and lung cancer. We focus our time and resources to help people stop using tobacco.

We know that detecting cancer at the earliest stage improves a patient's chance for survival. Making resources available to educate Alaska Natives about the importance of getting screened for cancer at the appropriate time and age, as well as allocating resources to provide early detection and screening services, is critical.

Once cancer is diagnosed, we must work together to ease a patient's cancer journey. As we all know, cancer affects not only the person diagnosed with cancer. It affects all of us---family, friends and community. We must identify resources so that patients and families can get the best cancer care as close to home as possible.

Delivering health care services in Alaska is expensive and difficult. Cancer treatment requires patients to be away from home, their family, friends and familiar surroundings—at a time when they most need them. The cost of treatment, as well as the cost of transportation and travel, dramatically increases the cost of cancer care. Cancer services must compete for limited funds with all other health care needs. A comprehensive, integrated cancer plan for Alaska Natives is important in our fight against this devastating disease. It will provide tools to help us identify resources to help prevent and treat cancer and to use those resources wisely.

We must work together to achieve our vision of cancer-free Alaska Natives. Just as we have overcome many deadly diseases like tuberculosis, we can defeat cancer. We can reduce the chance of being diagnosed with cancer by making healthy lifestyle choices. We can detect some cancers early and we can treat the disease with the latest therapy available. We can provide support to cancer survivors. We can provide quality palliative care to those whose cancer cannot be cured. In spite of all the fears and problems associated with the words "you have cancer," the cancer journey is not made alone--we make the journey together.

"Our patients appreciate each day as they live it. Not worrying about the future seems to help them better manage cancer treatment. They are very grateful for everything we do. We don't really know the difficulties they face in their villages because they don't complain. They share slowly. When they get to know and trust us, they talk about difficulties in day-to-day lives made more difficult because they have cancer."

Mel Hersman, RN, BSN, ANMC Oncology Nurse

Ethel Lund

Ethel Lund, 72 years old, is a Tlingit from the Kiksadi clan. Her parents passed away when she was young, and she was raised by her grandparents. Ethel has three children and three grandsons. She retired as CEO from the SouthEast Alaska Regional Health Corporation (SEARHC) in 2000 and lives in Juneau.

Ethel: I grew up in Wrangell, a small island town on a river. The river was rich with salmon and hooligan. We lived a subsistence lifestyle with plentiful crab, shrimp, deer and berries as well as the fish in the river. Everyone knew each other. Children ran freely, as there was always someone to watch over them.

My grandmother set a standard for me. In addition to speaking our Native language, she spoke and wrote in English and was the first secretary of the Alaska Native Sisterhood (ANS). My grandfather was the history and legend keeper of our clan. From him I learned our traditions and culture. He taught me that it was important to always use your talents and give back to the Tribe.

With the support of the local physician and the priest I attended the Good Samaritan Hospital in Oregon to become a nurse. In 1950 during my last semester of nursing school, I was diagnosed with tuberculosis (TB). I went back to nursing school after being hospitalized for a year and a half, but a recurrence of TB forced me to drop out. My grandparents were getting older and so I took a medical transcription course and returned to Wrangell.

In January 2002 I was diagnosed with breast cancer, discovered during a routine screening mammogram. The recommended treatment was a lumpectomy and radiation therapy. After the lumpectomy, I was told I needed additional tissue removed.

When I was diagnosed with cancer I felt the pressure of time to make decisions. I didn't want to spend seven weeks away from home for radiation treatment. I would have to be away from my support system just when I needed it most. Instead of a lumpectomy and radiation, I decided to have a mastectomy.

When I found out I had cancer, I needed to talk to someone who had faced cancer and understood my fear and anxiety. I needed to know where to get information to help me in my decision-making. All my life I had worked in the healthcare field and yet when I was

"I didn't want to spend seven weeks away from home for radiation treatment. I would have to be away from my support system just when I needed it most. Instead of a lumpectomy and radiation, I decided to have a mastectomy."

Ethel Lund

Barbara Searls

Barbara Searls, 50 years old, is a Tlingit from Juneau. She is the Chief Financial Officer for SEARHC. Barbara was diagnosed with breast cancer in 2000.

Barbara: I went for a routine screening mammogram and was asked to return in six months for another mammogram. When I returned, the results of the diagnostic mammogram required that I schedule a biopsy. I chose to get my care in Seattle where I could get a stereotactic biopsy. The biopsy was scheduled for three weeks later, but it seemed like an eternity to me. I needed another biopsy a week after the first one as doctors worked to decide the best course of treatment. I had the recommended lumpectomy, but the pathology report indicated that there was not enough tumor-free area where the cancerous tissue was removed. The physician recommended a bilateral mastectomy. I had the mastectomy followed by reconstructive surgery.

I have five sisters. Three of us were diagnosed and treated for breast cancer within two years of each other. We all had bilateral mastectomies. My other sisters are currently cancer-free. We had genetic counseling and found that we tested negative for two of the genes that correlate to a high risk for breast cancer.

I was very involved in the decision making process around my cancer treatment. I always got copies of the doctor's reports and reviewed them. I asked questions when I didn't understand something. It made me feel like I was part of the team caring for me. The cancer wasn't just happening to me—I was taking control of my disease.

No one can fight cancer on their own. It takes a lot of people to help heal cancer. So many people reached out to me, not just breast cancer survivors, but

"I was very involved in the decision making process around my cancer treatment. .... The cancer wasn't just happening to me—I was taking control of my disease."

Barbara Searls

diagnosed with cancer, I was just as bewildered as anyone.

I met with Barbara Searls, whom I knew from the ANS, and her sister who also had breast cancer. They brought me all kinds of information. They were both so positive. They told me "Cancer can be cured, it can be treated." They continued to support me through cancer treatment.

In 2002 my son was diagnosed with colon cancer that spread to his liver. Once again I had to deal with cancer. It was hard. I couldn't understand how the both of us could be diagnosed with cancer when there was no history in our family.

In some ways, I am torn. I want to put my cancer behind me and get on with my life. But if someone reaches out to me, I am available to provide support. When I can help cancer patients, I feel I am practicing what my grandfather taught me—to take my skills and experience and give back to others. The demonstration of courage by cancer patients and their families inspires me.

many other people too. It seems that women are always so busy taking care of others that it is sometimes hard to accept help and care. I knew it was important to let people help me.

Ethel called me when she was diagnosed with breast cancer in 2002. We had known each other through the Alaska Native Sisterhood (ANS) and she knew I was a breast cancer survivor. My sister and I met Ethel for lunch and talked about the decisions she would have to make and her choices. We were pleased that we could reach out to someone who was now facing the same bewildering and frightening life-changing decisions we had so recently faced.

Ethel Lund & Barbara Searls

Joan Orloff

Joan Orloff, 54 years old, is an Aleut born in Afognak. After the 1964 earthquake and tidal wave, the family moved to Port Lions on Kodiak Island. Joan was one of nine children and her father was a commercial fisherman. Joan and her husband, a commercial fisherman, have five children. The Orloff family spent summers fishing in Chignik Lagoon where they eventually built a home. They moved to Anchorage in 1987.

Joan: Afognak was a wonderful place to grow up. It was a remote village, serene and quiet. I remember walking on the beach on a clear night with a full moon and looking at the stars. Recently my children told me they remember the same peacefulness when we lived in Chignik Lagoon.

I was diagnosed with breast cancer in 2002. I found a lump in my breast and the doctor ordered an ultrasound. I was scheduled for a biopsy the day after I came back from vacation with my family. I didn't tell anyone. Just before my appointment I told my youngest daughter Janette. She offered to go with me, but I told her I was okay.

As I went through surgery and chemotherapy, Janette was with me all the way. She brought me fresh roses every week. She made sure I had something to eat every day. During chemotherapy, I got very sick for about a week. For three days I couldn't do anything. After that I forced myself to get up, eat and start moving around.

I grew up with the ocean and missed it when I moved to Anchorage. I missed it even more when I was getting treated for cancer. Between chemo treatments I flew to Kodiak to be by the ocean. I walked the beaches and listened to the gentle surf on calm days or pounding surf when the wind was blowing. It was so healing for me to be by the ocean and the tall spruce trees and be able to go berry picking with my family.

In the old Native hospital I saw ladies walking around wearing scarves on their head. I always wondered why. I really didn't know anything about cancer. Then I ended up wearing one of those scarves. I became one of those ladies. I looked around and said to myself, "I see a lot of survivors." I told my children "I'm going to be a survivor too. But I have to go through chemotherapy to get there."

When I was going through chemotherapy I met a lady who was also being treated for cancer. She was from the Pribilof Islands and was very afraid. We became friends right away. She told me she was scared and my heart went out to her. I took her to lunch and visited her in the room at the hotel where she stayed during treatment. The Oncology Clinic staff scheduled us for chemo at the same time so we could sit next to each other. They called us the "chemo twins." She said I made going through treatment a lot easier for her. She has gone home now to the Pribilof Islands but we are still friends and talk often.

Janette recently got married in Hawaii. Twenty-five of us got on the plane to go to Hawaii for the wedding. I had never been there before. I watched my daughter, who was my major support through cancer treatment, marry and start a new life.

"I grew up spending summers with Joan and her family in Chignik Lagoon where our families fished each summer. When you fish, you spend most of the time on the ocean and the rest of the time, it is always close to you. When you grow up around the ocean, it becomes part of your soul. When we face difficulties, we turn to the ocean for comfort, peace and reassurance of continuing life."

Brenda King

Joan Orloff with Brenda King & Janette Knutsen

Leslie Greene, Jr.

Leslie Greene, Jr, 36 years old, is an Inupiaq Eskimo who has lived in Anchorage all of his life. His family is originally from Solomon, near Nome. A large community during the early 1900s, Solomon is now a subsistence-use area for Nome residents. Les was only four years old when he was diagnosed with testicular cancer in 1972, a rare disease in a young child. His mother, Ruth Kalerak, cared for him.

Ruth: My son told me his stomach hurt and so I took him to the doctor in Anchorage. After tests, the doctor told me Les had cancer. It was a real shock. The doctors consulted with specialists in Seattle and they decided he needed surgery, chemotherapy and radiation. It was so hard to know my young son might not live. My husband could not handle the fact that our son had cancer and was not able to help me through the treatment process.

At first, I went through the motions of getting care for Les but I was in a daze. One day, a doctor said to me, "Look Ruth, the sun is out." I looked up and realized I didn't even notice it was a beautiful day. It woke me up and I knew I had to do everything to help my son. I asked the doctor, "Did I cause this cancer? My daughter eats the same food. Why did my son get cancer?" The doctor told me that I did not cause the cancer. They were puzzled too. It is usually an "old man's cancer."

My son had surgery and then radiation therapy and chemotherapy. It was important that he ate lots of iron-rich food to keep his red blood cells high enough so he could have his next round of chemotherapy. I fed him liver and fish. He ate liver the day before his weekly treatment. I always invited family over to have lunch so there would be "sunshine" for him. When he had chemo, I took him to a park to play first and back to a park afterwards to make it easier. He got sick from the radiation and chemo and couldn't eat very much.

My family took care of my daughter Sharon when Les was sick. We were Southern Baptists and the Baptist Convention called down to the States to request prayers. Every Wednesday they prayed for my son. My mother made dolls and slippers and other crafts. The minister next door would bring visitors to buy them. My mother would only sell them if they promised to pray for Les. She always felt that if it weren't for those prayers, my son would not have made it.

It is hard on families when a young child has cancer. So much time is spent caring and worrying about the sick child. It was hard on my younger daughter, because my parents always asked about Les and prayed for him. My marriage did not survive.

When the treatment was finished, the doctors told me there was nothing more they could do. My son went for check-ups every six months for several years and then once a year.

When my children got older, we went to camp at Solomon. My dad took Les hunting and fishing. In the Eskimo way, when Les caught his first fish, everyone stopped to build a fire. The fish was cooked on a stick over the fire and the elders ate it. This meant that the elders now had a grandson who could care for them when they could no longer hunt and fish.

My father died in 1986. On October 5, 1987, which was my father's birthday, Les' son was born. He named him Andrew after my father. In the Eskimo way, this is the best—the next person born is named after the person that died.

This cancer has been very hard on my son. He is only now beginning to understand how special he is. He is not a victim but a long-term cancer survivor and a model for other people fighting this terrible disease.

"My dad took Les hunting and fishing. In the Eskimo way, when Les caught his first fish, everyone stopped to build a fire. The fish was cooked on a stick over the fire and the elders ate it. This meant that the elders now had a grandson who could care for them when they could no longer hunt and fish."

Ruth Kalerak

Ruth Kalerak & Leslie Greene, Jr.

"A cancer diagnosis affects not just the patient but the entire family. The stresses associated with diagnosis and treatment are magnified by the distances from home and separation from family."

Frank Sacco, MD, ANMC Surgeon

FOOTNOTES:

1 Parran T, Elder MQ. Alaska's health: a survey report to the United States Department of the Interior. Pittsburgh (PA): University of Pittsburgh, Graduate School of Public Health; 1954.

2 Blot WJ, Lanier A, Fraumeni IF, et al. Cancer Mortality among Alaskan Natives, 1960-69. J Natl Ca Inst. 1975;55(3):547-554.

3 Fortuine, Robert MD, MPH. Characteristics of cancer in the Eskimos of southwestern Alaska. Cancer; February 1969

4 Average annual cancer incidence rates were age-adjusted to the US 1970 standard population. Comparisons of rates were performed using Mantael-Haenszel odds ratio and 95% confidence interval for determining the range of the odds ratio.

5 All rates are age-adusted, average annual rates. Age-adjusted: Rates have been mathematically weighted to allow comparisons of populations with different age distributions. Average annual: Cases for several years are added together and divided by the number of years to give an average annual number. This number is divided by population. This number is the rate of cancer cases. It is usually shown as per 100,000 population.

6 Lanier AP, Kelly JJ, Holck P, Smith B, McEvoy T, Sandidge J. Cancer Incidence in Alaska Natives thirty-year report 1969-1998. Alaska Med 2001;43(4):87-115.

7 Life Expectancy 1998: Alaska Natives 69.4 years; All Alaskans 74.7 years; U.S. all races 76.7 years. Source: Alaska Bureau of Statistics.

8 Lanier, AP MD MPH, Holk, P PhD MPH et al. Childhood Cancer among Alaska Natives. Pediatrics vol.12, no.5 2003,396-403.

9 Information on newly diagnosed cancer cases is based on data collected by registries in the NCI's Surveillance, Epidemiology, and End Results (SEER) Program and the Center for Disease Control's (CDC) National Program of Cancer Registries (NPCR).

10 Lanier AP, Holck P, Kelly J, Smith B, McEvoy T. Alaska Native Cancer Survival. Alaska Medicine 2001;43(3):61-9, 83.

11 Relative survival rates were calculated using the actuarial method in accordance with the National Cancer Institute SEER Program. 95% confidence intervals were compared to detect statistically significant differences between U.S. and Alaska Native rate estimates.

12 Day GE, Lanier AP. Alaska Native Mortality, 1979-1998. Public Health Rep 2003;118(6):518-30.

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16 Status of Alaska Natives 2004. Institute of Social and Economic Research, University of Alaska Anchorage, May 2004.

17 Kate Landis, Director, Southcentral Foundation (SCF) Breast and Cervical Program

This publication was written & produced by Christine A. DeCourtney, ANTHC

GLOSSARY OF CANCER TERMS

Adjuvant Chemotherapy – drugs given after surgery to help prevent cancer from coming back.

Benign - a tumor which is not cancerous; it does not invade nearby tissue or spread to other parts of the body.

Biopsy – the removal of a sample of tissue that is examined under a microscope to look for cancer cells.

Carcinogen – a substance or agent that causes cancer.

Cell – the basic unit or building block of human tissue.

Chemotherapy- treatment with cancer fighting drugs to kill cancerous cells.

Chronic – lasting a long time

Clinical trials – research studies that find better ways to prevent, diagnose or treat cancer using new drugs or medical devices.

Colonoscopy – a procedure that allows the doctor or nurse to look inside the rectum and the colon through a lighted tube.

CT scan – an x-ray procedure using a computer to make detailed pictures of areas of the body.

Diagnosis – the process using symptoms, lab results and physical exam to find out about a disease.

ENT Physician – Ear, Nose and Throat doctor who specializes in diseases of the ear and larynx, and other diseases of the head and neck—an Otolaryngologist

Genetic – inherited; having to do with information passed from parents to children through DNA

Hormone therapy – treatment that prevents certain cancer cells from getting the hormones they need to grow.

Immunotherapy – treatment to stimulate or restore the ability of the immune system to fight infection and disease.

Infusion – a procedure by which fluid or medication is given directly into a vein. If it is given over a period of time it is an intravenous or IV drip.

In Situ – cancer cells found in the uppermost layer of tissue, not invasive.

Invasive – spreading into healthy tissue.

Lymph nodes – small, bean-shaped organs located along the channels of the lymphatic system. Also called lymph glands.

Localized – cancer only found in the organ where the cancer started.

MRI – a procedure using a magnet linked to a computer to make pictures of areas inside the body.

Malignant – a tumor that is cancerous and has the ability to spread to other parts of the body.

Mediport---a surgically implanted device used to infuse medications and fluids (venous access device). For people who need frequent blood draws and medication, it eliminates the need to start an IV in the arm every time medication is needed or blood is needed for lab studies.

Metastasis – the spread of cancer from one part of the body to another part of the body.

Oncologist – doctor who specializes in cancer care.

Palliative care –addresses care needs of people with serious life-limiting illnesses such as cancer. It focuses on bringing comfort to the patient even when cure may not possible.

Pap test – microscopic examination of cells from the cervix. It is used to detect changes that may be cancer or may lead to cancer.

Primary Site – where the cancer first started.

Prognosis – the probable outcome of a disease; the chance of recovery.

Radiation Therapy – treatment with high-energy rays to kill or damage cancer cells.

Radiation Oncologist – a doctor who specializes in using radiation to treat cancer.

Remission – disappearance of the signs and symptoms of cancer. It can be temporary or permanent.

Risk Factor – something that increases a person's chance of developing cancer.

Side Effects – problems that may occur when treatment affects healthy cells such as nausea, feeling tired, vomiting, hair loss and mouth sores.

Stage – describes how far the cancer has spread from the original site to other parts of the body (in situ, local, regional, distant).

Stereotactic biopsy – a procedure that uses a computer and a three-dimensional scanning device to find a tumor site and guide the removal of tissue for examination under a microscope

Sigmoidoscopy – a procedure that allows the doctor or nurse to look inside the rectum and the lower part of the colon through a lighted tube.

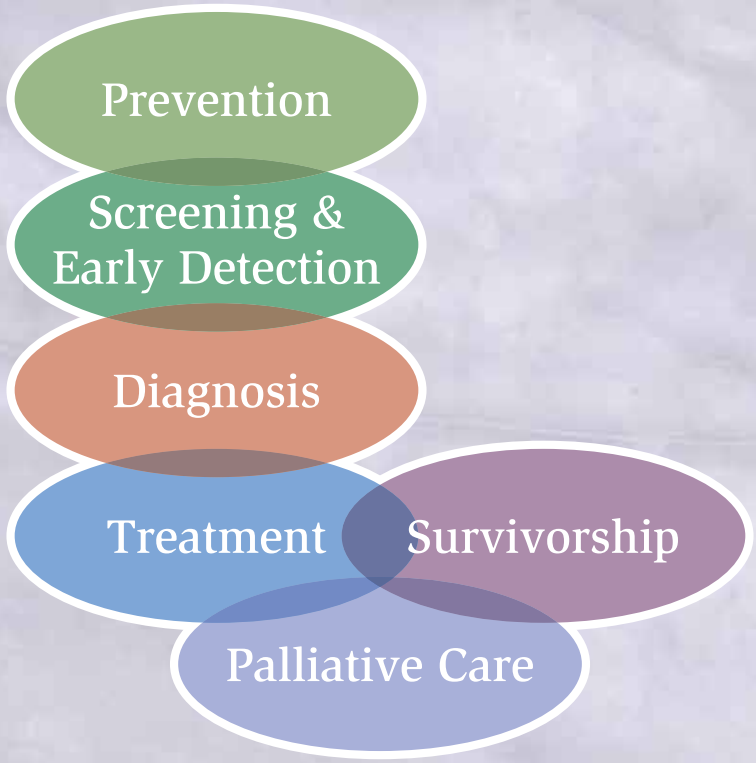
Survivorship – the period from the time cancer is diagnosed until the end of life.

Tumor – a mass of excess tissue.

Tumor Board Review- A treatment planning approach in which a number of doctors who are experts in different specialties review and discuss the medical condition and treatment options of a patient. In cancer treatment, a tumor board review may include that of a medical oncologist (who provides cancer treatment with drugs), a surgical oncologist (who provides cancer treatment with surgery), and a radiation oncologist (who provides cancer treatment with radiation). Also called a multidisciplinary opinion.

White blood cells – cells that help the body fight infection and disease.

CANCER CARE



CANCER PREVENTION & SCREENING

PREVENTION

- Don't smoke or use tobacco products
- Avoid exposure to tobacco smoke
- Limit alcohol consumption
- Increase the amount of fruits and vegetables you eat
- Increase physical activity
- Reduce the amount of saturated fat in your diet
- Talk to family members about the history of cancer in your family.
- Talk to your doctor if you experience unusual symptoms

SCREENING

- Mammogram for breast cancer
  Begin in your forties with screening every 1 to 2 years or follow your healthcare provider's recommendation
- Pap Test for cervical cancer
  Begin within 3 years after first sexual intercourse, but no later than 21 years of age; get screened at least once every 3 years or follow your healthcare provider's recommendation
- Colorectal exams at age 50
- Talk to your doctor about prostate cancer screening
- Talk to your doctor about cancer concerns and best screening options for you

Cancer Resources

National Cancer InstituteCancer Information Service (CIS)
Trained people answer questions about cancer and send out free cancer materials
1.800.4.CANCER
www.cancer.gov

American Cancer Society
Cancer information and support services
1.800.227.2345
1.907.277.8696
www.cancer.org

American Lung Association
Works to prevent lung disease and promotes lung health through education, community service, advocacy and research
1.800.813.4673 or 907.276.5864
www.lungusa.org

Native Cancer Information Resource Center and Learning Exchange (C.I.R.C.L.E.)
A cancer resource center for American Indians/Alaska Natives
1.877.372.1617
www.mayo.edu/nativecircle

National Patient Travel Center
Provides some free or discounted medical transport services
1.800.296.1217
www.PatientTravel.org

Chronic and Acute Medical Assistance (CAMA)
Pays for some health care services for adults and children who do not qualify for Medicaid
1.888.804.6330 or 907.269.5777

Angel Flight West
Provides free flights for some patients who can't afford public transportation
1.888.426.2643
www.angelflight.org

Office of Native Cancer Survivorship
Helps identify and coordinate resources for American Indian/Alaska Native cancer patients
1.800.315.8848 or 907.333.2071
www.ONCS.org

Cancer Hope Network
Matches patients with trained volunteers who have had cancer. Provides support and hope.
1.877.467.3638
www.cancerhopenetwork.org

National Alliance of Breast Cancer Organizations (NABCO)
Information and education resource for breast cancer
1.888.806.2226
www.nabco.org

Patient Advocate Foundation
Helps improve access to healthcare services
1.800.532.5274
www.patientadvocate.org

Susan G. Komen Breast Cancer Foundation
People supporting people committed to fighting breast cancer
1.800.462.9273
www.komen.org

Colon Cancer Alliance, Inc.
Fights colorectal cancer through patient support, education, research and advocacy
1.877.422.2030
www.ccalliance.org

Leukemia and Lymphoma Society
Support and information about blood related cancers
1.800.955.4572
www.leukemia-lymphoma.org

US TOO! International, Inc.
Support, counseling and education about prostate cancer
1.800.808.7866
www.ustoo.org

Lance Armstrong Foundation
Support for cancer survivors to live strong through education, public health, research and advocacy
1.512. 236-8820
www.laf.org

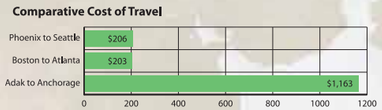
Air Miles to Anchorage

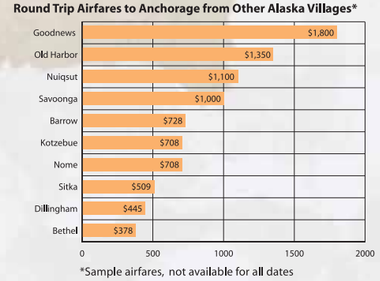
Access to cancer care in Alaska is made more difficult by the lack of roads. Cancer patients living in remote villages must fly from their village to a hub community and then onto Anchorage. Often the trip takes more than one day. The graphs below show an example of air travel from communities to Anchorage, which may require one or more stops to reach Anchorage.

Equivalent Distances of Travel

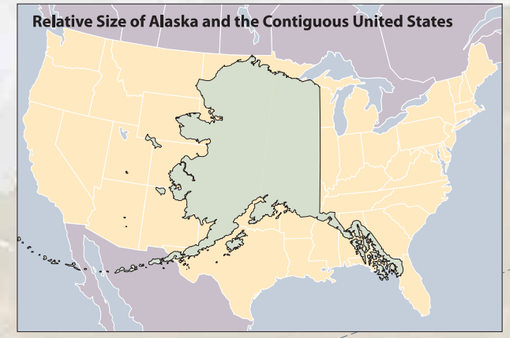
A woman living in Adak must travel to Anchorage to get a mammogram.[17] The flight takes over five hours and is only offered two-three times each week. The trip requires, at a minimum, three days. Frequent weather problems can delay the start or finish of the trip for a week or more. The distance for this trip is the equivalent of:

1. A woman traveling from Phoenix to Seattle by way of Los Angeles
2. A woman traveling from Boston to Atlanta by way of Washington D.C





*Sample airfares, not available for all dates



ARCTIC OCEAN
BEAUFORT SEA
CHUKCHI SEA
BERING SEA
NORTON SOUND
BRISTOL BAY
GULF OF ALASKA
PACIFIC OCEAN
ARCTIC CIRCLE

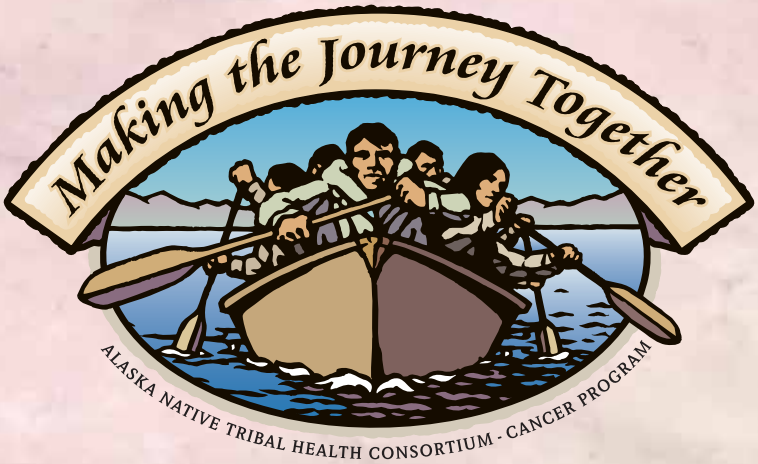
Barrow, Wainwright, Atqasuk, Point Lay, Nuiqsut, Prudhoe Bay, Kaktovik, Point Hope, Kivalina, Noatak, Anaktuvuk Pass, Arctic Village, Kotzebue, Kiana, Noorvik, Selawik, Ambler, Kobuk, Shungnak, Shishmaref, Diomede, Wales, Deering, Buckland, Wiseman, Venetie, Chalkyitsik, Fort Yukon, Evansville, Bettles, Alatna, Allakaket, Beaver, Birch Creek, Hughes, Stevens Village, Circle, Central, Brevig Mission, Teller, King Island, Huslia, Rampart, Livengood, Minto, Tanana, Eagle, Gambell, Savoonga, Nome, Solomon, White Mountain, Koyuk, Golovin, Elim, Koyukuk, Galena, Ruby, Nulato, Manley Hot Springs, Fairbanks, North Pole, Nenana, Shaktoolik, Kaltag, Unalakleet, Stebbins, Saint Michael, Delta Junction, Healy Lake, Dry Creek, Dot Lake, Tok, Tetlin, Tanacross, Lake Minchumina, Healy, Cantwell, Telida, Mt. McKinley, Chuloonawick, Kotlik, Bill Moore Slough, Hamilton, Emmonak, Alakanuk, Numan Iqua, Grayling, Takotna, McGrath, Medfra, Nikolai, Paxson, Northway, Mentasta Lake, Slana, Anvik, Shageluk, Chistochina, Nabesna, Mountain Village, Saint Mary's, Andreafski, Pitkas Point, Pilot Station, Marshall, Russian Mission, Ohogamiut, Holy Cross, Crooked Creek, Georgetown, Sleetmute, Stony River, Red Devil, Upper Kalskag, Lower Kalskag, Aniak, Chuathbaluk, Napamiute, Skwentna, Talkeetna, Gulkana, Glennallen, Gakona, Tazlina, Copper Center, Chickaloon, Willow, Sutton, Palmer, Wasilla, Susitna, Knik, Eklutna, McCarthy, Chitina, Valdez, Scammon Bay, Paimiut, Hooper Bay, Chevak, Newtok, Tununak, Umkumiute, Toksook Bay, Nightmute, Nunapitchuk, Kasigluk, Atmautluak, Akiak, Akiachak, Kwethluk, Bethel, Napakiak, Oscarville, Napaskiak, Mekoryuk, Tuluksak, Lime Village, Anchorage, Tyonek, Hope, Whittier, Tatitlek, Cordova, Eyak, Kenaitze, Nikiski, Kenai, Soldotna, Kasilof, Clam Gulch, Seward, Chenega Bay, Yakutat, Nikolaevsk, Homer, Seldovia, Port Graham, Nanwalek, Port Alsworth, Nondalton, Ninilchik, Pedro Bay, Kachemak, Iliamna, Newhalen, Kokhanok, Koliganek, New Stuyahok, Ekwok, Aleknagik, Twin Hills, Igiugig, Dillingham, Manokotak, Togiak, Levelock, Portage Creek, Ekuk, Clark's Point, Naknek, South Naknek, King Salmon, Egegik, Goodnews Bay, Platinum, Tuntutuliak, Eek, Kipnuk, Kwigillingok, Kongiganak, Kquinhagak, Cheffornak, Mekoryuk, Nightmute, Afognak, Ouzinkie, Kodiak, Port Lions, Karluk, Larsen Bay, Old Harbor, Akhiok, Pilot Point, Ugashik, Port Heiden, Chignik Lagoon, Chignik Lake, Chignik, Nelson Lagoon, Ivanof Bay, Perryville, Cold Bay, False Pass, King Cove, Sand Point, Unga, Pauloff Harbor, Akutan, Dutch Harbor, Unalaska, Fort Glenn, Adak Station, Atka, Nikolski, Attu, Shemya Station, Saint Paul, Saint George, Klukwan, Skagway, Haines, Yakutat, Juneau, Hoonah, Pelican, Tenakee Springs, Angoon, Kake, Petersburg, Wrangell, Sitka, Hyder, Kasaan, Ketchikan, Saxman, Klawock, Craig, Hydaburg, Metlakatla

- **Village, town or city**
- **Village with clinic** staffed by CHA/Ps
- ▲ **Village with subregional clinic** staffed by midlevel practitioners
- ■ **Regional Hospital** – provides inpatient, outpatient and ER services for common illnesses and injuries and may provide some surgical procedures
- ✚ **Alaska Native Medical Center** (ANMC) the referral/specialty hospital for the Alaska Tribal Health System
- Road

N

6/2004

SCALE IN MILES
0 50 100 150 300



When someone is diagnosed with cancer, a long, difficult journey begins. It takes time to confirm a cancer diagnosis, complete treatment, and deal with the after effects of the disease and treatment.
Cancer impacts everyone who makes the cancer journey, not only the patient, but family, friends and entire communities.

To honor the waterways that are so important to Native life, our cancer program logo shows a boat with a cancer patient in the bow navigating the way. Behind the patient are family, friends, healthcare providers and others supporting the cancer journey. The patient is the focus of the journey and takes charge of fighting the disease—spiritually, mentally, emotionally,and physically. However, the patient does not make the journey alone.
We make the journey together.

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