Son's effort keeps Barrow woman at home

by Jennifer Gordon

Tundra Times reporter

When Kate Negovanna, an Inupiat from Barrow, first started treatment at the Alaska Kidney Center in Anchorage, she said she would rather die than remain away from her family and homeland.

For the past year, however, Negovanna, 66, has been able to continue hemodialysis treatment in her own home through the Kidney Center's home treatment program and her 33-year-old adopted son, Ron Nalikak.

"She gave me 18 years of her life. It's the least I can do," Nalikak said of Negovanna. Nalikak went through the Alaska Kidney Center's six-week program last year to learn how to run the artificial kidney machine and take care of Negovanna.

Nalikak is a Dutch-German Inupiat who was adopted at birth. He said he knows his natural parents, but Kate and Silas, Kate's husband, have been his family.

Negovanna grew up in a nomadic family, travelling by dogsled across Northern Alaska. She can speak only a little English, said Nalikak, and Anchorage was strange to her.

When it seemed that Negovanna had stopped trying, Nalikak said, the family and doctors at the Kidney Center talked about home care. Nalikak said he was the only one available to spend the time needed to care for his mother—even though it meant giving up his job with the Alaska Eskimo Whaling Commission and putting his work as a firefighter on hold.

Barbara Carraher, a social worker for the Alaska Kidney Center, said that most doctors do not encourage hemodialysis treatment in rural communities.

Because Negovanna lives near the Public Health Service, Alaska Native Hospital in Barrow, it was decided to let her try hemodialysis at home. But while the doctors and nurses at the Barrow hospital come by to check

Negovanna's condition and can perform blood tests, only Nalikak is trained to fix the machine and regulate Negovanna's treatment.

"Ron is really out there on his own," said Carraher.

Nalikak stocks three month's worth of supplies in two metal cabinets, just in case of bad weather. He said that during the cold snap earlier this winter, the water was so cold that the heating unit went out in the machine.

Talking to the Kidney Center by phone, Nalikak and the doctors concluded that one of three parts in the machine needed to be replaced, so the parts were sent by airplane to Barrow.

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Hemodialysis

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Nalikak said that Negovanna went three days without dialysis while he fixed the machine — after five days

serious illness begins.

Nalikak said that when he first started learning about the artificial kidney, it was intimidating. He said it was confusing trying to figure out where all the "spaghetti tubes" connected. Now, however, he said he has figured out a system.

Every Monday, Wednesday and Friday, Nalikak gets up at 7 a.m. and sets up the artificial kidney. He rinses out the formaldehyde used to disinfect the machine, changes the tubes and then makes breakfast. After pancakes and coffee, Nalikak hooks his mother to the machine, starting the four-hour

treatment.

During hemodialysis, the artificial kidney is used to clean the blood of contaminants. Blood from Negovanna's arm flows through tubes into one of two chambers. The other chamber contains a cleansing fluid called dialysate. A membrane between the chambers allows only the waste from the blood to pass through to the dialysate.

Blood cells are too large to move through the membrane and only about two cups of Negovanna's blood are in the machine at one time. Nalikak said that once the process is completed he cleans the machine and takes water

samples for bacteria.

Water is an expensive commodity in Barrow, Nalikak said, but through the Barrow utility, Negovanna receives 300 gallons a week for free. He said that community and public services have made taking care of his mother much easier.

Living in Barrow and having to give almost constant care to his mother hasn't been the easiest job, said Nalikak. He said that often he has to take long walks to clear tension headaches. He has a son in Washington he said he would like to see, but it would mean taking his mother to Anchorage for two weeks and finding someone to take care of her.

Overall though, Nalikak said the relationship between him and his mother is special because she trusts

him explicitly.

Nalikak said that his mother's kidneys failed because of diabetes. He said she is getting weaker and has trouble seeing, but she is still the same person who took care of him when he was little.

The Alaska Kidney Center is a nonprofit organization. It treats more than 50 patients and is one of two treatment

centers in the state.