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BLIGHTED HOMELAND

Oases in Navajo desert contained 'a witch's brew'

Rain-filled uranium pits provided drinking water for people and animals. Then a mysterious wasting illness emerged.

By Judy Pasternak

Times Staff Writer

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Cameron, Ariz.

In all her years of tending sheep in the western reaches of the Navajo range, Lois Neztosie had never seen anything so odd.

New lakes had appeared as if by magic in the arid scrublands. Instead of hunting for puddles in the sandstone, she could lead her 100 animals to drink their fill. She would quench her own thirst as well, parting the film on the water's surface with her hands and leaning down to swallow.

Despite the abundant water, an unexpected blessing, her flock failed to thrive. The birthrate dropped, and the few new lambs that did appear had a hard time walking. Some were born without eyes.

Lois' husband, David, wondered whether the sheepdogs were mating with their charges. A medicine man, he also suspected witchcraft. He tried to fight the spell by burning cedar and herbs and gathering the sheep around the fire to inhale the healing smoke.

The livestock were not his only worry. A mysterious sickness was affecting the couple's two youngest daughters.

Laura, born in 1970, had a weak right eye and was prone to stumbling. Arlinda came along the following year and developed ulcers in her corneas by age 5. A few years later, she was walking on

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the sides of her feet.

At the Indian Health Service hospital, doctors were mystified. Experts concluded that both girls suffered from a rare genetic disorder.

There was another possibility, but no one considered it until many years later.

No one connected the children and the sheep.

Tainted oases

In the mountains and mesas of the Navajo reservation, mining companies drilled tunnels in the sides of cliffs to extract uranium for the nation's nuclear weapons program during the Cold War. But in the red and ocher sands around Cameron, where deposits were shallow, the ore was blasted out of the plains, creating pits.

As demand for uranium eased in the late 1950s, the U.S. government allowed the companies to leave without filling in the craters. The pits collected snowmelt in the winter and runoff from summer torrents. The holes, some as deep as 130 feet, soon formed oases in the desert.

Lois grew to depend on them as she ranged far from home, covering as much as 10 miles in a day. At dusk, she often camped for the night. She got in the habit of filling and refilling a small container with her drinking supply as she moved from one "lake" to the next, watering her herd.

Every few weeks, the Neztosies butchered one of the sheep. They ate each one down to the bones, which they sucked around the fire. They destroyed the lambs that could not walk.

Deformed animals were showing up in other sections of Dine Bikeiyah, Home of the People, as Navajos call their homeland. In areas around old mines, lambs and cattle developed shaking limbs, yellow eyes and white patches on internal organs that were discovered after slaughter.

Word of these strange developments did not reach the Neztosies. Navajo families tend to live miles apart from one another. They prize their privacy. Local officials heard occasional complaints about damaged animals, but no one discerned a trend.

Baffled doctors

Arlinda, nicknamed Linnie, had that "funny walk," as her family described it. At the Indian Health Service clinic in Tuba City, Ariz., doctors prescribed Vitamin A for her eyes and gave her goggles to wear. Classmates teased her, so she stopped using them.

When she stopped taking her supplements, her Vitamin A levels remained normal — but her corneas did not improve.

Laura had similar but milder symptoms and was small for her age. Her mother took her to the clinic

too. "Go home," Laura said she was told. "There's nothing wrong with you."

In truth, medical records show, the doctors were stumped. Something was affecting the girls' peripheral nervous systems, but what? Linnie and Laura were the youngest of nine children. None of their siblings or other relatives had experienced anything like this.

Like many Navajo families, the Neztosies led semi-nomadic lives. A rough-planked one-room shack served as home base for Lois' sheep-herding expeditions and David's long commutes to a sawmill in Flagstaff. There was no electricity. They got their drinking water from a well installed by the U.S. Public Health Service.

Around the time of the daughters' visits to the IHS clinic in the mid-1970s, the family's prospects were looking up. David had built a cinderblock house to replace the shack.

Laura started thinking about her future. Perhaps she would manage a hotel or become a stewardess. "I could be well-dressed and serve people," she remembers thinking.

In 1976, researchers from the University of New Mexico published an article in the journal *Archives of Neurology*. They had discovered a disabling illness that appeared to be hereditary. Corneal ulcers, muscular weakness and liver disease were among the symptoms.

All four cases cited in the paper were Navajo children. Two were siblings. "This does not constitute proof that the disease is genetically determined, but it seems likely," wrote the authors.

In the years to come, researchers would pronounce in more and more certain terms that the illness was purely hereditary. They called it "Navajo neuropathy." There was no cure.

Another family's loss

While the Neztosie girls were baffling their doctors, the Nez family braced for another death.

Leonard and Helen Nez lived most of the year at their sheep camp at the base of Tah-chee, a hill in the middle of the reservation.

They too had dealt with a spate of disfigured livestock — a calf with a crooked leg, another diagnosed with cancer of the eye, a lamb born with three legs, "kind of like an omen," one of the Nez daughters recalls.

Soon enough, the Nezes started losing children. First, in 1963, a stillbirth. Then, in 1969, daughter Dorinta and son Jerome died four months apart. In 1972, Claudia died. These three siblings had suffered from blurred vision, failing livers and limp muscles. None lived past a fourth birthday.

Three more Nez children were displaying similar symptoms. At the Indian Health Service clinic in Chinle, perplexed staff members asked Helen whether she engaged in incest, consumed alcohol while pregnant or suffered from mental problems.

No, she said, offended. None of these apply.

The doctors urged her to stop having babies, she said.

In the spring of 1978, the family's youngest, 2-year-old Euphemia, was in serious decline. By then, there was a name for the ailment. The IHS arranged for the child to undergo liver surgery in an Albuquerque hospital.

The treatment team included Russell D. Snyder, a pediatric neurologist at the University of New Mexico. Snyder was one of the authors of the article suggesting a hereditary cause for Navajo neuropathy.

But Helen, now 68, said Snyder expressed concern when she told him she lived near a uranium mine — an abandoned pit atop Tah-chee. Helen said he warned her that uranium was dangerous.

Snyder declined to be interviewed. In notes on the Nez family that he wrote in 1990, after treating the siblings for years, he included this observation: "A uranium mine was within one mile of the home where all these children lived, and uranium tailings were closer."

Until that conversation at the hospital, the Nez family had not considered the old mine a danger. Then Helen got to thinking: Their drinking water came from Tah-chee.

On July 31, 1978, Euphemia died. She was the fourth Nez child to succumb to Navajo neuropathy.

Unanswered prayers

In 1980, the IHS sent Laura and Linnie Neztosie to be examined by Snyder. Linnie was 9, Laura 10.

The girls spent two weeks at the hospital with their mother, and left feeling as bewildered as when they'd arrived.

In a letter to the reservation doctor, Snyder considered whether "heavy metal intoxication" was the cause of their problems. But Snyder concluded that "by far the most likely possibility is a hereditary" disorder — perhaps "partial Navajo neuropathy."

In 1983, the health service sent Laura and Linnie back to Albuquerque and Snyder. In their referral letter, IHS physicians wondered whether the girls should be tested for lead, arsenic or thiamine — all known to cause neurological problems at high doses. There is no record that they were tested for these or any other toxic substances.

By 1986, Linnie's fingers and toes tingled and tended to curl up like claws. It was becoming harder for her to walk, and her hands and feet were losing muscle tone.

"Clinical dx: Navajo neuropathy ... Prognosis: Guarded. Progressive disability expected," wrote

Stanley Johnsen, a pediatric neurologist who examined her in Phoenix.

Then Laura began to have stinging and prickling sensations in her limbs.

David Neztosie took the medicine man's view: Bitterness between him and his wife must be affecting his daughters. He left the house and the marriage.

For a year, Laura and her mother prayed. They tried traditional rituals and steamed inside a sweat lodge. The ceremonies, they hoped, would halt the strange sensation before it progressed.

One morning, Laura had trouble getting out of bed. Her fingers and toes had stiffened into hooks, like her sister's. They would not unbend — and have not since.

The older Neztosie children chopped wood for the fire and cleaned the house when they were home from Indian boarding school, but the two youngest "couldn't help our mom," Laura recalled. "We used to crawl around on the floor, on the sandy floor."

Disquieting discovery

In 1986, Donald W. Payne, an environmental health officer for the IHS, made a disquieting discovery.

Payne, then on loan to the tribal government, agreed to help a National Park Service ranger work on his water sampling technique. They tested 48 water sources around a national monument near Cameron.

What they found appalled them.

Uranium levels in the water at Cameron were as high as 139 picocuries per liter in wells and up to 4,024 in abandoned pits like the ones where Lois Neztosie watered her sheep and filled her drinking bottles.

EPA rules permit no more than 20 picocuries per liter in drinking water.

The water in many of the pits also had high concentrations of radium-226, a radioactive byproduct of uranium.

Payne had never seen the pits before. "I was amazed by the sheer size of the things," he said.

In reports to the tribal government, he wrote that "the Indian Health Service, as the primary public health providers for the Navajo people" should "make every effort" to warn residents not to drink from the shallow wells or let their livestock drink from the pits.

The tribe, Payne wrote, "must mount a concerted program to restrict access of livestock to the heavily contaminated pits and impoundments."

Charles A. Reaux, a regional IHS official, knew animals were not the only ones at risk; in a 1986 memo, he had written of "suspected human use" of the pit waters.

Reaux was reluctant to commit his agency's resources to uranium-related health hazards because the cost seemed open-ended. But on reading Payne's findings, he recommended that the health service "get involved in determining if there are contaminated water sites in Cameron ... and other areas," adding that the IHS "may also have to support this effort financially."

The suggestion died quietly.

Neither the tribe nor the IHS mounted the educational campaign urged by Payne. Navajos who were drinking from the pits or watering their animals there had no reason to stop.

Now retired and living in Maine, Payne says the government's inaction still bothers him.

The IHS "should have told them, and they should have found the money to give them water that was safe to drink," he said. "You don't just stick your head in the sand."

Staff members of the tribe's environmental commission showed photos of the water-filled pits in Cameron and elsewhere to their director, Harold Tso, a radio-chemist

Tso, now 68, said he was overwhelmed by other urgent problems, such as the piles of radioactive waste at old uranium-processing mills.

"I wanted to get out there" to see the pits, he said, "but I never did."

Focus on genetics

Medical research continued to focus on a genetic explanation for the mysterious wasting disease. In February 1990, the journal *Neurology* published an article on possible causes of Navajo neuropathy.

"No common environmental factors (i.e., water source, heavy metal exposure, toxin exposure, family occupation) have been discovered," the report said.

But the research team did not fully consider the possible role of uranium mining.

Steve Helgerson, then senior epidemiologist at the IHS, designed the study and was one of the authors. In a recent interview, he said the scientists ruled out a water source as the cause of the illness because no single well supplied all the affected families. The researchers did not explore whether the various water sources shared common contaminants.

Patients were screened for exposure to various heavy metals but not uranium. The scientists rejected "toxin exposure" as a possible cause because there was "no organized pesticide use out there," Helgerson said.

The only time uranium came up, he said, was in regard to "family occupation." Someone wondered whether the fathers had been miners and whether uranium exposure might have affected their genes.

That possibility was discarded because most of the mines were in the eastern part of the reservation, while Navajo neuropathy cases were five times more common in the west.

Helgerson said it didn't occur to him that most of the mines in the east were tunnels, whereas those in the west were mostly open pits. He hadn't heard about Payne's water sampling.

The research team's article noted the "familial pattern" among patients and concluded the most likely cause was "an inborn error" of metabolism.

The disease's course was inexorable, the researchers reported. Those afflicted usually died of liver disease. In two dozen cases studied, the average age of death was 10.

'I didn't know'

In 1992, a form letter from a lawyer arrived at the Neztosie household. Colorado attorney Cherie Daut was seeking clients among former uranium miners who were eligible for special federal payments for lung disease.

Daut invited residents to the Tuba City chapter house, the Navajo equivalent of a town hall.

By then, Laura had graduated from high school with a special-education diploma. Linnie's legs had worsened, and she often wept in pain. Lois put hot sand in a blue flour bag to soothe her youngest child's limbs until she fell asleep.

The Neztosies wondered whether the lawyer could help. Maybe she could push the IHS to offer more aggressive treatment.

On the day of her visit to the chapter house, Daut recalled, Laura struggled toward her in leg braces followed by Linnie in a wheelchair. Laura slammed her frozen fingers on the table.

"Please help me," she said.

Daut was struck by the sisters' appearance. It brought to mind a photograph she had seen years before of a patient with Minamata disease — the result of mercury poisoning that struck residents of that Japanese city after a chemical company dumped wastewater in the bay. Babies born to sickened mothers had twisted, shriveled limbs.

Daut told the sisters about her work. They got to talking about uranium and its impact on miners.

The Neztosies mentioned that mining had its benefits — the pits had brought them water. Daut thought of Minamata and began to wonder whether tainted water might have some connection to the crippled figures before her.

Daut sought help from lawyers in Colorado Springs, Los Angeles and New York City with experience in environmental litigation. In 1995, she filed suit in tribal court against El Paso Natural Gas Corp. and a subsidiary, Rare Metals Corp., which had operated some of the pit mines in the Cameron area.

The other lawyers recommended experts, including John F. Rosen, a professor of pediatrics and director of the lead clinic at the Children's Hospital at Montefiore in the Bronx.

The sisters traveled to Montefiore, where genetic tests found none of the most common mutations leading to inherited neuropathies.

In the fall of 1996 and spring of 1997, Rosen, toxicologist Paul Mushak and other scientists toured and tested the watering holes, which were still in use.

The water in the pits had washed over heavy metals and radioactive elements, creating a poisonous soup. The scientists learned that Lois drank from the lakes while she was pregnant with Laura and, later, with Linnie.

Mushak calculated that for each day in the desert that she drank 3 liters from the pits, she was exposed to uranium at levels nearly 100 times the federal maximum. The water contained high concentrations of lead, arsenic and cadmium.

She also received a dose of radioactive alpha particles that was probably 10 times the safety threshold for pregnancy or more, wrote radiation expert Daniel N. Slatkin.

When Lois drank from the pits, she pumped "a witch's brew" into her womb, Rosen said.

Eating the meat of sheep that had watered at the pits provided another pathway for exposure. Lois had even used the water to make infant formula for the two sisters.

"*Dooshilbeehozindala!*" Lois cried out in Navajo when she heard the news.

"I didn't know!"

Water connection

When the lawyers received the Indian Health Service registry of probable Navajo neuropathy cases, the list had 44 names. The oldest had been born in 1959, around the time the abandoned pit mines began filling with water.

It was the first that Linnie and Laura knew of others like themselves.

The legal team hired James W. Justice, a researcher at the University of Arizona and a former IHS epidemiologist, to interview the families of people on the list. He found relatives of 41. He wasn't told which were participating in the suit.

Justice said a clear pattern emerged as he assembled the mundane details of their histories, habits and lifestyles: When mothers drank polluted water while pregnant, they bore children with Navajo neuropathy. When they were away from the old mines during their pregnancies, they bore healthy children.

"In one case after another, it went back to water," Justice said.

Lois Neztosie, for example, had avoided the mines when she was pregnant with her older children because of the blasting. She spent another pregnancy housebound during a year of deep blizzards while a relative cared for the herd. The family's drinking water that season came from melted snow.

It was the same for Helen Nez, Justice found. Six of her 10 children had developed Navajo neuropathy. Of the four healthy ones, she had been pregnant with two daughters before the family began drinking water that had flowed through the old pit mine atop Tah-chee. She had carried both healthy boys while living away from the mine.

Unknown to Justice or the Nezes, a federal inspector independently documented that groundwater in the area had been contaminated by the Tah-chee mine.

Four other families joined the Neztosie sisters' suit against El Paso. The Nezes were not among them because El Paso had not mined at Tah-chee.

Cedar and Theresa, the two oldest surviving Nez children with Navajo neuropathy, felt trapped and angry. Each had the same hooked toes and fingers as the two Neztosie sisters.

Theresa was so determined to walk without leg braces that she sought treatment from a chiropractor in Gallup, N.M., enduring a painful hour's drive each way. Cedar lectured his alcoholic brother, telling him that he should be grateful that his body functioned and shouldn't abuse it with drink.

In 1996, Theresa died, followed by Cedar a year later.

In all, Helen and Leonard Nez lost six children to Navajo neuropathy.

Dwindling hope

With the lawsuit dragging on, Linnie was losing hope. Rosen had found her a place in an off-reservation rehabilitation center in Colorado, but she yearned to return home. By this point, she wore diapers. "Mom can't handle you no more," Laura told her.

Then Linnie broke a Navajo taboo. She told Laura: "I just wanna die."

Laura remembers replying: "Linnie, don't say that. I don't want you to think that way."

In June 2000, the telephone rang in the middle of the night, and an older Neztosie sister, Nora,

answered. She told Laura that Linnie, just shy of 30, was gone. They held each other and cried.

El Paso had fought all the way to the U.S. Supreme Court in a successful effort to have the case moved from tribal to federal courts, where the nuclear industry enjoyed partial protection from liability. The federal court appointed a mediator.

Within a few months of Linnie's death, El Paso agreed to pay a total of \$500,000 to the four families without admitting liability, tribal court documents show.

Justice presented his findings at a conference of the Public Health Service Commissioned Officers Assn. in 2001. Yet the view that Navajo neuropathy was purely inherited continued to have its adherents.

It did seem logical. There were multiple cases within families. The syndrome had appeared suddenly, the way a "founder effect" disease might.

A "founder effect" begins with one person who develops a genetic mutation in a nondominant gene. That person passes it on to his or her children, who pass it on to theirs. Because the gene is recessive, the trait does not surface unless two descendants have children together, usually generations later.

A team from Tufts University and another from Columbia University examined three genes that might cause the disease. But they reached a dead end each time.

Then the Columbia group found that liver tissue from three Navajo neuropathy patients showed reduced levels of mitochondrial DNA, a condition that can lead to progressive organ damage.

This year, in the September issue of the American Journal of Human Genetics, the Columbia group announced a breakthrough. An Italian scientist had found a previously unknown mutation in a recessive gene that caused mitochondrial disease of the brain and liver.

Testing DNA samples from six Navajo neuropathy patients, Columbia neurology professor Salvatore DiMauro and his colleagues found the same mutation.

Still, some aspects of Navajo neuropathy do not fit the genetic theory — or suggest that heredity is only one factor.

For one thing, Italians with the genetic mutation suffered liver disease, but not the curled hands or loss of sensation seen among Navajos.

After Navajo neuropathy appeared in 1959, reported new cases increased through the 1960s, '70s and '80s, then tapered off in the 1990s and have all but disappeared — an arc that mirrors Navajos' exposure to contaminated water from pit mines.

The increase in cases occurred while the mines were being abandoned and were filling with water. The drop-off roughly coincided with the filling-in of the pits by the tribal government.

If the illness was exclusively hereditary, "there should be more, not fewer, cases as the years go on," and then the numbers should level off, said Richard I. Kelley, a pediatric neurologist at Johns Hopkins University who has identified "founder effect" diseases among the Amish.

DiMauro said it was possible that, as with many diseases, a combination of genetic and environmental factors was responsible. "There are still things to be explained," he said.

Kelley said his review of the scientific literature and medical reports from the Neztosies' lawsuit "has left me convinced that this is an environmental disease."

Even if a genetic mutation turns out to play a role, "the mine exposure is a unique stress," he said. "The disease may not be manifest except under those conditions."

A true survivor

Laura Neztosie, now 36, is the oldest surviving patient from the Indian Health Service registry.

She and her mother live in two-stoplight Tuba City (population 8,000). Laura drinks protein shakes and takes a periodic table of vitamins, as recommended by Rosen. Her mother dresses her every morning. Nearly blind in one eye, she flips her Bible open with one gnarled hand to find her favorite verses, highlighted in pink.

She also cares deeply about the healing ceremonies held under the wide dark skies outside town. Lois parks her truck close so Laura can watch the dancing from the front seat.

Later, at home, Lois lights a pipe packed with dried mint and mountain flower and holds it to Laura's lips. Lois waves the sacred smoke toward her daughter.

After years of firelight and kerosene lamps, they have electricity. Treated water runs from kitchen and bathroom taps.

But old habits hang on. One day, on her way to visit Linnie's grave on the sagebrush plain, Lois pulled over at a familiar spot. While Laura waited in the truck, the mother walked a short way from the dirt road and lifted boards that had been placed over a natural watering hole to keep coyotes away.

Lois was thirsty and didn't hesitate. She leaned down and drank deeply from the spring.

judy.pasternak@latimes.com

Times researcher Mark Madden contributed to this report.

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