

# Going the Distance

## Bringing Cancer Care to the Navajo Nation



**W**hen people are diagnosed with cancer on the Navajo Nation<sup>1</sup>—a 27,000-square-mile expanse of land that extends into Utah, Arizona, and New Mexico—many of them must travel hundreds of miles to receive even the most basic cancer treatment. Now, a small team of community leaders and national experts are working to change the situation.

The first-of-its-kind oncology program on any Indian reservation in the country opened its doors this year at Tuba City Regional Health Care Corporation, making cancer care available locally for up to 200 patients annually who will receive culturally appropriate clinical treatment and patient assistance.

### **In the Beginning: Discovery Meets a Common Goal**

In January 2017, Kim Thiboldeaux, CEO of the Cancer Support Community, was at the White House facilitating a session on reaching the underserved as part of the Cancer Moonshot initiative when two women approached her and said, “We have to talk to you; there’s a little-known secret that there is no cancer care on any Indian reservation in the United States—physically *on* the reservation,” Thiboldeaux said. She didn’t believe it could be true. Soon after, she and her team began investigating.

“They were, in fact, correct, and they knew exactly what they were talking about. Those two people were Brandy Tomhave and Dr. Johanna Dimento, and they had both worked with the Navajo Nation for many years. I was the naïve one in the conversation, and they quickly educated me,” Thiboldeaux said. “I

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was stunned, and equally shocked to learn that cancer care is not in the scope of the Indian Health Service.”

The Indian Health Service provides primary care to Native American people but *not* specialty care, which means that those living in the region must travel great distances off the reservation to places like Flagstaff, Ariz., for example, to receive cancer treatment. In some cases, people must travel as far as Tucson, Ariz., hundreds of miles from the western, central, and northern region of the Arizona reservation. Some people simply forego treatment altogether because of the hardship. Some die as a result.

And it’s not just that it’s a long distance in miles; there are other challenges that affect this patient population in particular.

## A History of Exemplary Care, Just Not Cancer Care

As the sole provider of acute and ambulatory healthcare and Level III trauma care on the Navajo Reservation, Tuba City Regional Health Care Corporation is a 73-bed hospital located in northeast Arizona on the land known as the Colorado Plateau. The facility serves as a regional referral medical center for more than 75,000 Native Americans, which are the Navajo, Hopi, and Southern Paiute living in a 6,000-square-mile area

The hospital was constructed in 1975 and since then has provided the community with comprehensive inpatient and outpatient and emergency services; primary care, dental, and ophthalmology services; orthopedics; obstetrics/gynecology; oral surgery; eye surgery; dermatology; and general surgery procedures. Approximately 49 percent of the surgeries performed are outpatient and/or ambulatory surgical procedures.

In addition, the hospital has two mobile healthcare units that supplement primary healthcare to the reservation's most remote locations. About one-third of all homes in these areas lack plumbing, electricity, and a telephone, and nearly 80 percent of all roads are unimproved dirt roads that are seasonally inaccessible.<sup>2</sup>

To say that the Navajo face barriers to cancer care is a gross understatement. Although Tuba City has historically provided excellent medical care in primary care and family medicine, the hospital has not been able to serve people locally who receive a cancer diagnosis.

The staff of medical providers includes surgeons; general medical officers; internal medicine; psychiatrists; pediatricians; family practice physicians; obstetricians; ear, nose, and throat specialists; orthopedic surgeons; and urologists. Dental staff includes general dentists, endodontists, oral and maxillofacial surgeons, pediatric dentists, dental assistants, and hygienists. The nursing staff includes registered nurses, licensed practical nurses, nursing assistants, community health nurses, nurse practitioners, nurse midwives, a certified registered nurse anesthetist, and public health nurses.

There's just one thing missing—cancer care.

### Barriers to Care

To say that the Navajo face barriers to cancer care is a gross understatement. Although Tuba City has historically provided excellent medical care in primary care and family medicine, the hospital has not been able to serve people locally who receive a cancer diagnosis.

Lynette Bonar, CEO of Tuba City Regional Health Care Corporation, is intimately aware of these challenges. Bonar is 100 percent Navajo. She grew up in California, served in the military, and worked as a registered nurse at a hospital in Missouri where she raised her family. She previously was credentialed in case management and oncology from the American Nurses Credentialing Center and moved to Tuba City to live on the reservation there. She's been at Tuba City Regional Health Care Corporation since 2003, first as a nurse case manager and now as its CEO.

A year before Bonar came to Tuba City Regional Health Care Corporation it became an independent hospital through self-determination, making the hospital free to make local decisions based on input from the community, its patients, its staff, its doctors, and the hospital board, instead of the Indian Health Service.

The hospital now is considered a "tribal organization" and, through its governing body, Tuba City made a contract with the U.S. government through the Indian Health Service to take over the responsibility to deliver healthcare. "The reason why they [Tuba City Regional Health Care Corporation] did that is because they wanted to make decisions locally on how we take care of patients," Bonar explained.

### Cultural Care in Community

In 2015 Bonar said the hospital started seeing different issues come up with people who had cancer. "The area's environment is unique in that there's a lot of things that were done around here that I think affects the environment. There was bomb testing in the 1950s and the fallout from that testing has impacted the soil and water supply," she said. "It affected a lot of people in the Southwest. There are still more than 550 open abandoned uranium mines." Her senior executive team includes 11 people. "Nine of us are Navajo, and out of that nine, about seven of us had a family member die from cancer," Bonar said. "That's a lot."

Bonar recalled a story of a young woman who volunteered at the Navajo Hopi Health Foundation. Bonar was shocked to hear that she had died of cancer after refusing treatment simply because she feared that her children could lose their jobs as a result of traveling the long distances required for her to get treatment. "Even the people who she did have within her family really couldn't afford the gas to take her back and forth," she said. "This person died because there's no access locally for cancer." Once she heard that, Bonar asked, "How many people is this happening to?" Some are fortunate. They have family who live in Flagstaff or Phoenix with whom they can stay while they receive treatment. But not everyone has that luxury.

Though patients receive excellent care in those places, and have for many years, Bonar explained, "They need somebody who speaks the language, because probably about half our people have Navajo as their first language. Approximately a third speak Navajo completely and don't understand English," Bonar said. "Our hospital is culturally sensitive to their needs as far as tradition and language and food and really takes their time with

them more than anywhere else I've ever seen that delivers healthcare.”

Bonar said the hospital also pays special attention to the specific dietary traditions of the people they serve, like mutton, corn, squash, and other local vegetables and grains.

Tuba City Regional Health Care Corporation recently received a grant to begin an Office of Cultural and Language Preservation. Around 100 of its support workers are fluent in Navajo, and staff are taught medical terminology in Navajo. “We provide competency testing every year to them so that they can speak fluent Navajo and talk to our elders or anybody whose first language is Navajo,” Bonar said.

The hospital's Office of Native Medicine employs case managers to help patients connect with traditional healers, because more than half of the people believe in Navajo traditional practices. Having prayers and ceremonies before, after, or during treatments and surgeries is non-negotiable. “The integration makes them feel more confident about coming over here and having what we would call more modern Western medicine healthcare,” Bonar said.

“I worked in Missouri as a case manager, and when we had an issue with a patient, it was really just the patient and maybe a family member,” Bonar said. “Here on the Navajo Nation, when they have a family meeting, you might have 10 people show up, because their understanding is to try to figure out what's going on, how it's going to affect them, and how do they all need to get together to help.” The meetings can take up to an hour, Bonar said.

When patients have to be referred to far-flung cancer treatment centers, these cultural needs often are not taken into consideration.

### Feasibility Study and Lack of Data

When Tuba City decided to move forward with its feasibility study to begin looking at how to bring cancer care onto the reservation, “it was very difficult to find numbers, because everybody's been leaving here for treatment, and we don't get that information back,” Bonar said. The hospital has a hard time getting information from the state tumor registry, so it's hard to identify and address the real issues, environmental or otherwise.

“Is there an issue more than likely from uranium?” she asks. “Because a lot of the types of cancer that we have are higher than the normal rate for the U.S. in the GI tract, gall bladder, liver, intestines, and kidney,” which she said seems to be rising every year. But again, they can't prove it without the data to back it up. Providing care locally will enable them to track outcomes to better serve their patients' needs and address them at the policy level.

### Payment Model Reform

As part of Tuba City's effort to bring care onsite, the hospital has recently renovated a modular trailer to house 6 infusion chairs and administer chemotherapy to approximately 200 patients annually. The hospital is doing it on its own because specialty care is outside the scope of the Indian Health Service, although

the agency does provide some funding for tribal members to receive care outside of the reservation.

“Indian Health Service is underfunded all the time, so if we ask them for more money for specialty care, it would need to be taken away from something else,” Bonar said. “It's just hard for them [the Indian Health Service] to say, ‘OK we'll give you more money, but then, let's not fund dental.’”

“We have to work with the [federal] government to figure out how, because right now, we send our patients down south. It's costing the government an arm and a leg to do that, because we're going to providers that are charging us whatever they want, and the government is paying it,” Bonar said. “We do have some funds to cover some of those things, but we'd rather do it here because the care is better and it's local. We have the ‘triple A’: accessibility, affordability, availability. It's all right here.”

“What we really need is a better payment model from Medicare, because we know that we [Tuba City Regional Health Care Corporation] can deliver cancer care at a better value than sending patients to places where they mark it up at 15 percent. And we know that the care will be good when it's delivered by their own families and workers here within the community,” Bonar said.

“We're really working with drug companies to see if we can get people on patient assistance because Medicare's not going to pay for it [treatment],” she added. “And Medicaid, we're waiting for them to start the specialty drug reimbursement,” which occurred in April 2019.

This is where Brandy and Jeff Tomhave come in.

### Advocating for Payment Reform

The two attorneys formed the consulting firm The Tomhave Group to ensure that American Indians have equal access to health, education, and justice. They were instrumental in getting a Medicaid waiver in the state of Arizona to expand the reimbursement of services on the reservation.

“We helped them [Tuba City Regional Health Care Corporation] develop their facilities, improve their old hospital building, and find the funding for a new outpatient center,” Brandy Tomhave said. “Whenever you do something like that on an Indian reservation, it will always require some level of federal approval because the federal agencies have oversight of everything that happens on an Indian reservation, and then additional funding from Congress.”

Tomhave helped lead the effort and write the language that created the tribal waiver in Arizona that not only preserved Medicaid benefits for American Indians when other Arizonans had their Medicaid benefits cut or their eligibility reduced but also expanded the eligibility and services that were offered, which has become a Centers for Medicare & Medicaid Services (CMS) model that now is being used elsewhere by some tribes in California and Washington.

“It's the first American Indian Waiver that expanded services and really protected the most vulnerable populations and expanded Medicaid for them,” Tomhave said.

“Even after the American Indian Waiver, specialty drugs were not included,” she said. “We were able to get a state plan amend-

ment approved by CMS through the Arizona Health Care Cost Containment System,” which is the state’s Medicaid authority.

“That will enable us to sustain this project through reimbursement, because absent this, we wouldn’t otherwise be able to get Medicaid reimbursement for cancer drugs, which kind of kills the project before it starts.” Tomhave said.

### **Creating Cultural Cancer Care**

That initial meeting at the White House forged a partnership that led to Cancer Support Community creating a culturally adapted version of its cancer support model specifically for the Navajo. Cancer Support Community previously has created culturally adapted programs for communities in Tokyo and Tel Aviv.

Last year Thiboldeaux and her team visited Tuba City and the reservation to identify its specific challenges, meeting with staff and traveling out into the reservation with nurses and outreach staff to begin to understand the culture, reading specific literature, and making a commitment to listening and learning.

“A crucial element will be integration of traditional medicine and healing techniques with modern medicine,” Thiboldeaux said.

The Cancer Support Community distress screening tool, Cancer Support Source, which is geared to the community setting, will be modified with questions and scales adapted to the Navajo culture.

Cancer Support Communities around the country provide weekly support groups, but that model is unrealistic on the Navajo Nation. The key will be to maximize time and resources when patients come in for regular medical appointments.

The Cancer Support Community also will work to support practical needs, like “clean water, firewood, and other things that we’re exploring,” Thiboldeaux said. “People need gas cards,” for example.

“I truly hope that not only are we going to get this model stood up but that it is going to be a model for other reservations across the country and other Native Americans and Native American communities across the country,” Thiboldeaux said. “Of course we want to raise millions of dollars for this effort and we want to build a beautiful building, and we want radiation oncology, and we want a linear accelerator. But we have to take it step by step.”

Thiboldeaux and others are hoping that their efforts will create a snowball effect as awareness continues to grow. Awareness is already spreading, and so the light at the end of the tunnel seems to be getting brighter for the Navajo. Thiboldeaux said, “We’re taking a team out there, for example, the University of Pennsylvania Department of Radiation Oncology; a team from their radiation oncology department wants to learn more and see how they can help. ... Pfizer did an employee fundraising effort, and the money that it raised is going to allow us to buy one of those chemo chairs.” Eisai has come through with funds to help patients with housing and travel.

Two nationally board-certified oncologists will provide comprehensive cancer care to patients at Tuba City Hospital. Dr.

Frank Dalichow and Dr. Johanna DiMento, another husband and wife team, will move from their home in Baltimore, Md., to Tuba City. Dr. Dalichow previously worked for the Indian Health Service in Tuba City and then as an internal medicine doctor there. Dr. DiMento worked in Flagstaff as an oncologist for several years. They both have finished a fellowship for oncology and hematology.

### **Far-Reaching Impact**

“What’s interesting to note is that this effort already provides ancillary benefits to other practices of medicine for other diseases,” Brandy Tomhave said. “We didn’t get a state plan amendment to reimburse cancer drugs; we got a state plan amendment to reimburse specialty care drugs and so that includes other diseases as well so there’s a broader benefit beyond cancer.”

“The broader impact is that we are changing tribal healthcare policy by providing a model of what can be done at a tribal healthcare facility on the reservation and, in so doing, that will enable the Indian Health Service to figure out how it can be done and the cost of doing it so that hopefully it can include, someday, oncology within its own budget,” Tomhave said. “Short of that, at least start to coordinate with other agencies on trying to work with them to make oncology available on reservations.”

Of the 575 federally recognized tribes in the United States, “access to cancer treatment on a reservation really only becomes an issue for those tribes that are so large and so remote that having to drive off the reservation causes suffering for tribal members,” Tomhave said. “So then you’re really talking about large land base reservations or some of the other reservations that may not be large but they’re awfully remote.”

“I can’t characterize for you how many of the 575 fit that description, but it’s a subset. We’re not forcing a policy issue or conversation about a policy that would require the federal government to contemplate providing cancer treatment on site for 575 tribes,” she said, putting the issue into policy perspective. “That’s not the case. We’re looking at something closer to probably a dozen.”

### **Moving from Ground Zero**

“There are a couple of levels of discussion that we are just now beginning to approach. Number one is education. I don’t think that it’s actually occurred to anybody what it means to not have any access to cancer treatment if you’re a large tribe and you’re a remote tribe,” Tomhave said. “What does that mean for patients and their families? It’s just not a question that has been asked, much less answered, in the past. That’s really where we’re at right now; that’s ground zero,” she said.

“There’s a health question, and then there’s the justice question. It’s a question of equity and neglect. And that is a discussion that should happen wherever people are talking about patients and cancer.”

“When the big dollars went out from the federal government to the states to build up a cancer infrastructure for treatment and research, tribes were not contemplated, and that’s not unusual.

Most big marquee federal initiatives have historically always forgotten about tribes,” Tomhave said. “The Ryan White CARE Act is one example, and then typically, decades later, somebody puts their hand to their forehead and realizes the oversight. By that time the world has moved on.”

“Everyone else has been able to get the resources and build the capacity needed for their communities to address the problem of [cancer] except tribes. So we come to the table decades after the conversation has moved on and when the resources have all been used up. Now we are trying to address federal policy to create new resources, and that’s a real challenge,” Tomhave added. “In so doing, we will create resources within federal agencies so that other tribes that want to do the same thing that Tuba City is doing won’t have to start this conversation at Ground Zero.”

“Whatever we’re able to do with and for the Indian Health Service to create new funding within its annual budget will benefit all tribes in that it will make these resources available. These resources will be the result of a change in federal tribal health care policy,” Tomhave said. “Ultimately what we want is to be able to provide the best cancer treatment available to Navajo patients where they live, work, and pray and so that they don’t have to drive the same distance as Washington, D.C., to New York City to get chemotherapy.”

### What’s Next?

“My hope for them [the Navajo] and my hope in the future is that patients prospectively don’t suffer the way that Navajo patients have in the past due to challenges that no one should face. It’s not only the distance,” Brandy Tomhave said. “It is language barriers; it’s cultural barriers.”

Tomhave provided another example of a woman she spoke with, a mother, master weaver, and a former uranium miner. An abandoned uranium mine still blows radioactive dust into her home and onto the property where she lives, her sheep graze, and her vegetables grow.

When she had to travel to Flagstaff for six weeks of cancer treatment, she often was so sick that they would just take her from chemo to the emergency department to spend the night and then take her back for chemotherapy the next morning.” The family spent the night in their truck each night. “It’s important for policy makers to understand when they say, ‘Well, you can just go off reservation to get care,’ what impact that has on families. Persons going off reservations is a hardship.”

“We struggle to find [a community] comparable to the Navajo Nation in terms of size and demographics. We had to go all the way to the other side of the globe to find one, and it’s Sierra Leone. It’s nearly identical to Navajo in size and the physical number of road miles,” she said. “Percentage of road miles that are unpaved. Percentage of homes without electricity and water. The poverty and unemployment rates are very similar. I found that startling. I worked for 20 years and just discovered this year that the only major difference for our purposes is that in Sierra Leone, there’s cancer treatment, but on Navajo, there’s not.”

“Trying to change federal policy, especially now, is more difficult than ever. We can’t wait for federal policymakers to catch up with us, so we are moving forward, and we’re launching this program [Tuba City Regional Health Care Corporation] with the limited resources that we have.”

And regardless of the progress that’s being made, the fact remains that Tuba City has a Go-Fund Me page to raise funds.

“The federal government has very little to offer today, so we’ve turned to the private sector. And my hope is that tribes in the future will not have to fight a war on cancer by holding a bake sale, which is what we essentially must do, because in the 21st century, a Go-Fund Me page is the old-fashioned bake sale,” Tomhave said. “I don’t think that a small tribal healthcare provider should have to try to figure out how to penetrate social media and raise money, \$5, \$10, \$25 at a time to be able to provide cancer treatment locally.”

“My hope is that people on reservations will dare to expect reasonable access to 21st-century medicine like any other American.” 

*Amy Hindman is a freelance writer with more than 10 years of experience writing in technology, healthcare, and oncology.*

For more information, visit [thealth.org/cancer](http://thealth.org/cancer). To donate, visit: [gofundme.com/launch-oncology-on-navajo](http://gofundme.com/launch-oncology-on-navajo). Find additional resources from Cancer Support Community at [cancersupportcommunity.org/resources](http://cancersupportcommunity.org/resources).

### References

1. Official Site of the Navajo Nation. History. Available online at: [navajo-nsn.gov/history.htm](http://navajo-nsn.gov/history.htm). Last accessed May 5, 2019.
2. Chaco P. Roads and transportation on the Navajo Nation. Available online at: [obamawhitehouse.archives.gov/blog/2012/02/15/roads-and-transportation-navajo-nation](http://obamawhitehouse.archives.gov/blog/2012/02/15/roads-and-transportation-navajo-nation). Last accessed May 5, 2019.

### Editor’s Note

As we went to press with this article, ABC News reported that Tuba City Regional Health Care Corporation’s new cancer treatment center welcomed its first patient in June 2019. Read more about this story online at: [abcnews.go.com/Lifestyle/wireStory/navajo-nation-cancer-center-cuts-patients-travel-time-63992312](http://abcnews.go.com/Lifestyle/wireStory/navajo-nation-cancer-center-cuts-patients-travel-time-63992312).