

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Navajo Nation: The First Cancer Center on a Reservation'

Description:

Join us as we speak to Dr. Johanna DiMento and Dr. Frank Dalichow, oncologists at the first cancer center on a reservation in the United States. In this episode, the doctors share about the realities of cancer care for Native American communities. They also discuss how they were able to bring cancer care to the Navajo and Hopi tribes, and the importance of inclusivity and culturally appropriate care for this population.

Transcript:

Elissa: Welcome to *The Bloodline With LLS*. I'm Elissa.

Edith: I'm Edith.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today we will be speaking to Dr. Frank Dalichow and Dr. Johanna DiMento about the very first cancer center on a tribal reservation. Drs. Dalichow and DiMento are medical oncologists and hematologists who were instrumental in bringing cancer care to the Navajo Nation through the Specialty Care Center at Tuba City Regional Health Care Corporation. They have a passion for addressing health disparities and providing expert care to underserved and rural communities. Welcome Dr. Dalichow and Dr. DiMento.

Dr. Johanna DiMento: Thank you.

Dr. Frank Dalichow: Thank you.

Elissa: So, what got you interested in working with Native American and rural populations?

Dr. Dalichow: This is Dr. Dalichow. I first started working here in Tuba City Regional Health Care Corporation when it was still part of the Indian Health Service. And I came here as a primary care physician directly out of residency in 2000 and worked here for 11 years, taking care of Native American patients with diabetes and high blood pressure and began to notice that many of our patients were developing cancer. And that's what got me interested in cancer and the lack of services that were available out here.

And what I mean by that is when our patients were diagnosed with cancer, they were sent off the reservation for treatment. And we live in a very isolated area here. We're far removed from major urban centers, and patients would have to travel great distances to access services, often 100 miles down the road where the closest cancer center is in Flagstaff or even further than that, 200 miles down the road where there are specialty cancer services available in Phoenix.

So that really began to bother me, and that is why I eventually decided to go back and do a fellowship in oncology. And it was always my dream to come back here and work in Tuba City in a cancer center dedicated just to this area and this group of patients.

Elissa: So, I saw in the article that there tend to be disproportionately high rates of some cancers, including multiple myeloma, a blood cancer, in Native American populations. In your experience, has that been what you've been seeing as well?

Dr. Dalichow: Yes. We see some very interesting epidemiologic trends in the incidences of cancer. Our patients here have a very low tobacco use prevalence or smoking prevalence. I would estimate that less than 1% of our patient's smoke cigarettes, so we don't see a lot of lung cancer and head and neck cancer out here. In fact, it's very unusual to see a lung cancer at all, which is very unheard of in a cancer center. When we do see lung cancer, it's often unrelated to tobacco. So that's one thing.

The other thing is we see higher incidences of myeloma, we see higher incidences of liver cancer, we see high incidence of gastric cancer as well. And we don't really quite understand exactly why that is occurring. We have many theories and ideas, but nothing is really known yet about this area and why we're seeing disproportionately high incidences of some cancers and not others.

Elissa: That would be really interesting to follow throughout the years, to see if there are studies done to see why there are these high rates of certain cancers there.

Dr. Dalichow: Absolutely. And one of the reasons this has not really been studied is when patients were diagnosed with cancer, they were sent off the reservation. And they were sent all over the state here in Arizona and all over the state in the Four Corners region to New Mexico and Colorado. So, there's really no one central registry for our patients where we can kind of study what types of cancers are being diagnosed here. The recordkeeping is very incomplete and spread out amongst four different states' tumor registries, and that is one of the things that we hope to rectify during our work here.

Elissa: So how did the cancer center come about at Navajo Nation?

Dr. DiMento: This is Johanna. I did my training down in Tucson at the university there; and when I was down there, Frank was working up here as a primary care doctor. And it's a five and a half hour drive one way from Tucson to Tuba. So, it's a long way, a long way down to Tucson.

And when I was starting to complete my fellowship, I always knew I wanted to take care of cancer patients. That's been my calling since I was 13. It's just who I am. And I knew that's what I wanted to do. And with Frank being up here, I wanted to come up here and start a cancer center. I was very naïve, and I thought, well, that's where I want to go and work. Let's just do it.



But things just were not in place yet to be able to do that. So, what I did was I worked at the closest place. I worked in Flagstaff. And working in Flagstaff meant that any patients from the Navajo or Hopi reservations up here, around Tuba City, that needed cancer care or hematology care, and that included benign hematology issues like anemia and such, they had to drive all the way down to Flagstaff to get their care.

Half of our patients in Flagstaff were from the Navajo Nation, and they were Navajo and Hopi; and I remember thinking why don't we bring our clinic up there. And I advocated for that at the practice that I was at in Flagstaff, but there just was no interest in that.

So, I always knew I want to go up to Tuba. And then when Frank decided to go back to do a fellowship, and he loves hematology. My passion is oncology; so, I felt that we'd be a perfect match and were married, to bring this cancer care up here to Tuba City.

I give the credit for the fact that we have our cancer center here to our CEO, Lynette Bonar. She's Navajo. She has worked in the cancer field in the past. She's a nurse. She's former military, and when she became the CEO, Frank and I looked at each other and said, "She has the vision to know what care is necessary up there." And with her guidance, with her vision, with her discussions with the hospital board, with the fact that so many people up here have had family members or personal experiences with cancer, and they know the challenges of driving down, finding the gas money, finding the time, having family come with them and escort them down to their care way down in Flagstaff, they all knew that this was something that should occur.

And it did. And we started caring for patients two years ago here. What I'd also like to just add a little bit about what Frank had said about the recordkeeping and how it was incomplete and scattered. As soon as we started here two years ago, that's the first thing we did. We started keeping track of patients, deidentified, but we started

keeping track of how old are our patients when they get various cancers? Where did they live at the time? What stage were they diagnosed with? What was their treatment, and were they able to pursue treatment? And what sort of outcomes did they have from their treatment?

And that's something that we've been able to track, and we do that on a daily basis. In fact, I have to let you know that right before we joined this podcast today, even though Friday is not technically a clinic day for us, I got a call from one of our surgeons about a gentleman with a new rectal cancer. Frank got a call from a primary care doctor with a gentleman with a new pancreatic cancer.

And these are patients who will be getting their care right here in their own community with this little cancer center here which is in their town, which is part of their hospital. Half of our staff are Navajo and speak Navajo, and that is something that they would not be able to walk into a cancer center and see the local Navajo art on the wall. They didn't see that. They didn't have that connection when they were going off the reservation for their care.

We have interpreters. In fact, our nursing assistant speaks Navajo. She's right there. I could say, "Hey, Christy, come here. Can you interpret for our grandma who's 75 and tell me what is going on with her?"

I think you can hear the passion in my voice. I think you can realize that this is the most gratifying job I've had in the 20 years that I've been a cancer doc because we are able to give this care right here in their town. And I am so grateful and thankful to our CEO, to our hospital board, to all the people who have been involved and recognize this as a project that needed to happen. The fact that we are the first cancer center on an American Indian reservation makes me proud and disgusted because this should not have been so long in the making, and we should not be the first and only.

This should occur everywhere in our United States. Getting to your cancer care should not be your biggest barrier. Your concerns and your heart and your soul and your emotions need to be focused on healing yourself. The same thing for all your loved ones and your caregivers. Having challenges to get to the cancer center should not exist.

Edith: Dr. DiMento, you gave me chills. It's very wonderful.

Lizette: Definitely.

Elissa: I think a lot of people in the larger cities take that for granted that it is so easy to go to your local cancer center or even have the satellite clinics that are still close by to you. And I can't even imagine having to go 200 miles away for your treatment. It's shocking really.

Dr. Dalichow: Yeah, and it's not just the distance either. Most of the roads out here are unpaved and dirt roads. So just even the first couple of miles, until you make it onto the pavement are a challenge. So, our patients have to prepare far in advance to go to any appointment. And if it rains or if it snows or if the roads are muddy, they can't go, and they're stuck at home.

And add on top of that, that many of our patients don't speak English. In fact, 50% of our patients don't speak English, and they need to go with a family member who needs to take time off work to go translate. If they go off the reservation, because they don't have translators there. Many of our patients' homes don't have electricity or running water and the unemployment rate is very high out here. And patients just don't have the funds to put gas in their tank to be able to go to appointments that are far away.

So many of our patients just give up and say it's too difficult. I can't go with a family member. I can't afford to buy gas to go to my appointment. The roads are muddy, and I can't even drive even if I wanted to. So many of our patients in the past have

just given up. They were given the diagnosis of cancer, often in advanced stages, and it was not unusual for patients to say, "I can't afford it. I don't want to be a burden on my family," and they would just stay at home and die of untreated cancer at home.

And that was one of the things that really, really bothered us. And that was really the reason for us to create this cancer center. And that's why we're here.

Lizette: Wow, and that was going to be my next question actually, doctor, because you mentioned that you started gathering information about cancer patients prior to the cancer center really taking on these patients. And I was just wondering, prior to this cancer center opening, how did patients even pursue these treatments? That's one of the things that you were looking into just because of all these barriers and not just barriers, even what you were talking about, Dr. DiMento, about the community. Being in the community, having the community trust and Dr. Dalichow mentioning that, you speak the language. That's really important, especially with cancer care, trying to be a part of your own treatment team. It's really important to be able to communicate with your treatment team.

Dr. Dalichow: Absolutely. And although neither of us speak Navajo, Navajo is a very difficult language; and I'm sure you know that it was even used as a code during World War II that was unbreakable by the Japanese. So, it is a very difficult language to understand. I only speak a few broken words at best.

So, yes, being able to communicate with our patients in their native language with a certified translator is extremely important, rather than having a family member go with them who may not be able to directly translate all the complicated cancer terminology.

And often I might just add that translator may be a young underage child that's going with their grandma, which is really a travesty, I think. So, we have translators here that can accurately and effectively translate into Navajo. And that's extremely important.

Dr. DiMento: And like you said about that trust element, you really hit the nail on the head there. When my momma was diagnosed with her first cancer, she initially saw an oncologist; and she just didn't have a connection with that oncologist. And then her next oncologist, she had quite the connection with.

And as a cancer doctor, I thought of that many times through my career. It's the art of medicine. You know what that patient needs for treatment for their cancer. We all practice by the NCCN Guidelines, National Comprehensive Cancer Network Guidelines. We know as board-certified hematologists and oncologists what treatments our patients need.

However, the art of the medicine is always knowing your patient and knowing what their wishes are and what's important to them and what their bucket list is and fitting the treatment to them. And that's where the art of medicine comes from, and that's where the trust from your patient comes from.

And I know from having worked off the reservation in this field, and I know now from working here in their home. I live in this town. I live right across the street in some of the housing. I know the difference in knowing that I am connecting with my patient in their trust level. I am connecting with them to know what it is they need and what it is they need from me.

And often that might be my saying, "You have fought the fight. You have done everything. We are going to take care of all your symptoms, and we are going to make you feel as well as possible for as long as you have." And those conversations, if you don't start out with that trust element, you are not going to be able to help and guide your patient. And that is something that I feel that I can do here, as I've not been able to do anywhere else in the U.S. in my career.

The other thing I want to say too is that our staff here, who we are so blessed to work with, they feel the way we do. We all have a heart for where we are and what we're doing and to have this staff where we are all that, we're a team taking care of our

patient. We all see different aspects of what our patient needs and what the caregivers need.

We have a case manager who also speaks Navajo, and she meets with our patients in the first visit. She figures out what supportive care they may need. Perhaps they need home health. Perhaps they need gas cards. And we can give out gas cards that can help our patients with the expense of gasoline, just getting to and from our cancer center here from where they live.

Because like Frank said, some of our patients might even live 100 miles away from our cancer center here in Tuba. And those gas cards can be so helpful. And the money for the gas cards comes from donations to our foundation, our Navajo Hopi Health Foundation.

Edith: How has a cancer center been welcomed by people who live in Tuba City and the surrounding area?

Lizette: Were you welcomed with open arms?

Dr. Dalichow: I would say that we were more than welcomed. And many of our patients have told us, how necessary a center here is. And we get that kind of feedback all the time, how glad they are that we're here.

Having said that, there is a certain reluctance for some patients to come here. And you know, nobody wants to talk about cancer, whether that's Native Americans or Caucasians. And sometimes we do encounter the occasional patient that doesn't necessarily want to come here.

Dr. DiMento: I don't think that they're a majority because most of our patients who are initially diagnosed, it would be through our surgeons who we work very closely with and we have a monthly tumor board with, or it would be through primary care doctors. And they just pick up the phone and let us know, "Hey, Frank, Johanna, Mrs.

So, and So's coming to see you. She's got a mass in her breast" and those kinds of referrals that we get very early in the process.

I think what I do want to say is that very rarely, but sometimes our patients might go down to Flagstaff and be seen in the hospital there and get a diagnosis of cancer. And then what we have seen is then they want to transfer their care to us. They want their care here in Tuba. That has happened often.

Edith: That's great.

Lizette: Are they aware that you are there and that you can diagnose cancer?

Dr. Dalichow: Oh absolutely. Yes. We're very closely integrated in our hospital with all our departments. Tuba City Regional Health Care is a 73-bed hospital. Although it is in a very isolated area, we have a wide variety of services available here. We have all the primary care specialties, such as family medicine, internal medicine, gynecology. We have specialty services like orthopedic surgery, obstetrics.

Dr. DiMento: Neurology.

Dr. Dalichow: We have nephrology as well. We have dialysis. We work together very closely with many departments and get referrals from all of them and work with a wide variety of physicians here.

Dr. DiMento: But sometimes, as Frank said, our patients can be diagnosed in late stage. And I just saw a woman recently. She came in and for six months she had been losing weight and bleeding, and she was diagnosed with stomach cancer. By coming into our Emergency Department and getting a CAT scan, and it was clear what her diagnosis likely was, she was sent straight from our Emergency Department down to Phoenix to a surgical oncologist, which is a subspecialist that we don't have here in Tuba and they're also not in Flagstaff. So, she went down to Phoenix.

After she was seen by the surgeon there and had her surgery, and then when she

needed chemotherapy after that, we're called quite often by the surgeons down in Phoenix because we've been here for two years, so now we know the surgical oncologists, we have their cell numbers, and they'll call us and say, "Hey, Mrs. So and So did well with her surgery I'm waiting for her final path (pathology), but I do think that she or he, whoever the patient may be, is going to need chemotherapy, but it's a cancer diagnosis and sending them back to you to care for them."

So that happens very frequently.

Edith: Is it open to others outside of the reservation?

Dr. Dalichow: Well 98% of the people that live here in Tuba City are Native American, and there are two main tribes that we take care of – the Navajo tribe and the Hopi tribe. And we have a mix of both tribes that we see. And it's been a while since we've seen anyone who's not Native American. I would say 100% of our practice is Native American, and that's just who lives here.

Elissa: Are you incorporating traditional and cultural treatments in your practice?

Dr. Dalichow: Oh yes.

Dr. DiMento: Absolutely.

Dr. Dalichow: Yeah, it's not uncommon for our patients to tell us they want to see a Native American medicine man, it's usually a man, and want to defer treatment for a couple of days until they have a ceremony. And of course, that's totally okay with us. We even have a medicine man here on staff-

Elissa: Oh!

Dr. Dalichow: -at our hospital as well. So, we work very closely with any patient that wants to incorporate spiritual practices into their treatment plan.

Dr. DiMento: That's a whole department at our hospital, as well as the interpreters.

They're in our department as well with multiple people who work in each. Absolutely. I've had patients say, "Yeah, I don't want to start my chemotherapy until I have my ceremony." And we completely encourage it. There's absolutely no reason to get in the way of that. That would be analogous to someone having a strong religious belief that they wanted to go to mass, say, before they started their chemotherapy. Those are the kinds of things that I find fascinating. And to answer your question, absolutely that's part of their care, yes. And it's accessible right here at our hospital for them.

Lizette: That's great.

Elissa: I think that's just so incredible that you have a medicine man in your practice.

Dr. DiMento: Through the hospital, yes, uh-huh.

Lizette: Yeah, I think what I'm hearing from both of you is that you're very patient-centric, which is something that I think every physician should be, and it's very good to see and good to hear from you, as well as the collaborations that you have with other hospitals close to you that are also serving this population.

Dr. DiMento: I feel blessed to be able to work in a facility where I can be patient-centric in that we're not being rushed. I've been in other places where there are so many patients to see in a day that you can be rushed, or you get way behind because you're giving the patients what they need. Here, I feel that we set this clinic up in a such a way that it can and will always be patient-centric. I love your phrase patient-centric. You're exactly right.

Lizette: And in your history of working with cancer patients in rural communities, what are the differences and similarities with Native American communities and other rural communities?

Dr. Dalichow: Well, our practice is a rural-based practice. So, we have many of the same challenges that any rural practice would have, and that being the distance, you know. And this is not unique to Native American reservations. This would be true for

any rural area in the US. The distances sometimes are huge, especially out here in the western states. So that's not necessarily different out here.

What is different is the fact that a lot of our patients, like I had mentioned before, don't live on a paved road or their home doesn't have running water or electricity, so you have to be especially careful to give them instructions and supplies so that if they become neutropenic, they have the ability to wash their hands with alcohol-based sanitizer or wipes or things like that. So, we often have to think beyond what are just basic things that we often take for granted living outside of the reservation. So, there are many differences that exist out here as well.

Dr. DiMento: What I'm thinking of as Frank said that is, I have a young lady with rectal cancer, and I asked her if she was having any bleeding when she had a bowel movement, and she told me she wouldn't know because she uses an outhouse. Or when we say things like, "You want to flush your toilet twice after chemotherapy," there like, "We don't flush our toilet. We have an outhouse." These are things that I think a lot of people don't appreciate.

Since being here, I get in the shower in the mornings, and I have warm water. I have hot water, and I can take a shower. So many of our patients, the people who live here haul their water. They have to go to the central area and fill up these huge tanks that you see in the back of their trucks and take it home. That's their water. And when I was helping out during the COVID epidemic, I was making results calls because it had to be all hands-on deck for our community because we were hit so hard with COVID, especially in Spring last year. I was making these calls, and I spoke with a grandpa, and he was about 75. And I explained to him that what's recommended is that you wash your hands for two minutes, and he said to me, "We cannot wash our hands for two minutes. We don't have that much water that we can do that." And he said, "We can use the sand to clean our hands. We can pick up the dirt and the sand." And I thought about that from a biochemical standpoint, and I thought, wow, that is fascinating.

But just these little things that we often as a society in the US don't think about differently that our patients that's part of their life and that's how they live. And I appreciate and respect that so much.

Elissa: So, I'm curious what happens with insurance and paying for care? You just talked about people having to use outhouses and not having running water. I'm curious about how they end up paying for care.

Dr. Dalichow: Yeah. That's a great question. The Federal Government pays for all the care for Native Americans here that live on the reservation. And that was a treaty that was signed sometime in the 1800s where the US government promised to provide healthcare for all Native Americans. And amidst all the treaties that were broken by the United States that they made with Native Americans, it is the one treaty, one promise that they have sort of kept by creating the Indian Health Service.

But that being said, the government would often only pay for primary care that was available on the reservation, and Native American patients were often on their own when they had to access care off the reservation – specialty care, like cancer care, or cardiology care, or things like that. And they would often have to resort to state programs like Medicaid or Medicare to pay for their care.

Us being on the reservation, we're obligated to provide all care, free of charge that we do here, and we don't really worry too much about that one particular issue.

Everybody that comes in our door doesn't get charged a dime for any of the care that we provide here. That's really one of the really great things about working here and one of the hassles that we don't have to deal with.

Dr. DiMento: Yes, yes.

Dr. Dalichow: We still have many challenges. Although we don't charge our patients here, we still have to collect reimbursement. And that has been a huge challenge as well because we answer to many different agencies – the Federal Government, the

state government as well and we're still working out some of the challenges on how to collect reimbursement. But we never charge any of our patients for any of the care that we provide here.

Elissa: So how do you think that we can continue to expand access to care for Native American and rural communities around the US?

Dr. Dalichow: I think that one of the challenges will ultimately be reimbursement. The reimbursement rates here are quite low. It's a whole web of rules and regulations that have to be navigated in order to get reimbursed for care out here. The Indian Health Service is not set up to pay or reimburse for specialty care. They're more focused on primary care, so there's quite a bit of work that has to be done in Washington, D.C. to try to reform that. That's certainly one area that needs improvement before more rural centers could be established.

And then I think we need to listen more to the Native American communities and find out exactly what they want and what they need. And they need to tell us what they want in their community. And that's exactly the way that this cancer center was established. The community here wanted a cancer center and told that to the board that runs our hospital. And our CEO, Lynette Bonar, took that and made this cancer center happen. So, we need to be listening more to what Native American communities want and make that happen.

Elissa: Those in Native American communities that could be listening to our podcast right now, do you think that that's what they should do is kind of rally their community together in their particular area on the reservation to try to get more cancer centers around the US and more local cancer centers for them?

Dr. Dalichow: I do. I think it needs to come from the community, and once the community buys into that and supports it, then it can happen. And that will perhaps put pressure on the government to be more accommodating and to provide the funds

to establish more cancer centers in rural areas, especially on Native American reservations.

Elissa: And I know we said that you were the first cancer on a reservation. Are you still the only cancer center on a reservation in the U.S.?

Dr. Dalichow: To my knowledge, yes. Alaska has a very excellent cancer center as well. It is not technically on a reservation. It's located in Anchorage, which is a large city in Alaska. But they also almost exclusively take care of Native Americans, so perhaps they're the closest one. By the way, they were also in existence before us. But to my knowledge, we're the only cancer center on a Native American reservation.

Elissa: Well, I hope that continues to expand. It sounds like it is a much needed service for so many of our communities around the U.S.

Dr. Dalichow: Absolutely.

Dr. DiMento: Yes.

Edith: On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to Native American tribal members who may be facing a new cancer diagnosis for themselves or a loved one? How would you give them hope for the future?

Dr. DiMento: One thing that I say to all my patients, I learned this from a woman years ago. She had breast cancer and needed chemotherapy. It was early stage; she was going to be cured. And she told me that I had said to her early on in her treatment that I and our team would do everything we could to get her through it. And I say that to my patients often. I let them know that we're here for them. And this is really no different, this is no different for someone who's Navajo or Hopi or other patients that I've seen in my profession. Letting them know that we've done this before, we're expert at this. I remind my patients, "This is Tuba City, true; this is a small, little town, but this is the same treatment recommendation that you would get a



Memorial Sloan Kettering or MD Anderson in Houston." I give them that reassurance that what we're doing for them here in our little rural area is what they would get somewhere else and that we've done this. We're expert at doing this, and we know how to help them, and we'll do everything we can to get them through it. Again, that's no different from what Frank or I have said to our patients in other places of the U.S.

Elissa: That's wonderful. Well thank you so very much, Dr. DiMento and Dr. Dalichow. We just so appreciate talking to you today. Loved hearing about the very first, and sounds like only, cancer center on a reservation in the U.S. We hope that community members will be listening around the U.S. today and really start rallying their community so we can get more, and we can really increase the access to care for when patients find themselves with a new blood cancer diagnosis. So, thank you again so much. We appreciate you.

Dr. DiMento: Thank you.

Dr. Dalichow: Thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes. This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.



Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to [LLS.org/PatientSupport](https://lls.org/PatientSupport). All of these links will be found in the Show Notes.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.