

If you're new to NETwise, we highly recommend you go back and listen to the first episode in this series. It goes over the basics of neuroendocrine tumors and how they're treated. And you can find a whole library of episodes on different topics at netrf.org/podcast, where you'll also find infographics and videos that expand on this material.

If you have a story to tell about your own NET journey, please email us and let us know - podcast@netrf.org

Patients travel from far and wide to visit Dr. Heloisa Soares. She's a medical oncologist with expertise in neuroendocrine neoplasms, and she works at the University of Utah Huntsman Cancer Center in Salt Lake City.

Her patients come from all over the mountain west -- in addition to Utah, they travel from locations in Idaho, Montana, Nevada, and Wyoming.

Many of them live in rural areas, and don't have access to care close to home.

Soares: *When I talk to my patients here, they tell me that they might not have any clinics in their area. That the closest healthcare clinic that they have could be an hour away or so forth, or there's only one doctor for the area that they are.*

It's typical to travel to see a specialist when you have a disease like NENs. But for patients who live in rural places, they have no choice but to travel long distances, even for basic care.

Dr. Soares estimates that about half her patients live in rural areas.

Soares: *I often ask this question and I hear, oh, the closest hospital to me is about two hours away. So they really do have to drive to the closest cancer center or university hospital, tertiary hospital that they have. And that's when coming, driving 400, 500, 600 miles comes into place because they really don't have an option.*

This is just one of the challenges that makes accessing care difficult for patients who live in rural areas.

Whether or not a patient has access to care is one of the most important factors in how their cancer journey plays out. It is crucial for timely diagnosis and effective treatment of neuroendocrine neoplasms. And when you live in a rural place, that access can be complicated.

You're listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF.

In each episode of this podcast, we share expert information and patient perspectives to help neuroendocrine cancer patients and caregivers navigate their journeys.

We often talk about how important it is to seek out specialized care for NENs - but we don't often talk about how challenging it can be to access that kind of care.

In this episode, we're going to focus on barriers to care that people in rural areas tend to face.

Welcome.

The word "rural" might bring to mind things like small towns, farms, and dirt roads. It might describe the mountain town you visited on a family road trip, or the rolling fields you saw out the airplane window on a flight from one city to another.

The defining characteristic of these places is low population density.

97-percent of the U.S. is rural, and only 20 percent of the population lives there. That's an average of only around 17 people per square mile.

There are plus sides to this low density: communities tend to be small and close-knit, there's easy access to nature, and you can see the stars at night.

But there are also downsides. Because people are few and far between, so are resources. This can include everything from grocery stores and gas stations to schools and medical care.

Soares: *When we talk about rural medicine, we think about the patients that are not in a metropolitan area, and don't have, therefore, very many times very easy access to care and live in an area that the population density is much smaller.*

Rural care is an important issue to consider. Roughly 60 million Americans live in rural parts of the country, and not having easy access to care can make a big difference in a patient's outcomes. This is true for any disease, and especially true for neuroendocrine neoplasms.

Dr. Julie Hallet is a surgical oncologist specializing in NETs at Sunnybrook Health Sciences Centre in Toronto, Canada.

Hallet: *It's a disease that can have a huge impact on quality of life if the tumor is not well controlled from the beginning. With a disease like neuroendocrine, which I like to call a chronic disease, where you aim for control, it's important to get a diagnosis to initiate the initial treatments. But then to also monitor carefully and keep people monitored so that when there's changes, we can react to them quickly. And that can make a difference in how people feel, how long they live, and how long their tumor can remain under control.*

Dr. Hallet has done research on disparities in NET care and access, [including a study published in 2015 that looked at whether or not living in a rural area impacted outcomes of NETs.](#)

Hallet: *We looked at patients that live in rural communities, which were defined as communities with less than 10,000 habitants and over two hours from major urban centers. And then we looked at people with different socioeconomic status.*

And what we found is for people who live in more rural areas or people with lower socioeconomic status, survival and recurrence-free survival after neuroendocrine tumor diagnosis is lower.

In addition, [an Australian study published in 2019](#) also found that patients from rural areas had worse clinical outcomes compared with those from metropolitan areas.

And in 2024, [a multi-institutional study from the US neuroendocrine tumor study group](#) looked at survival disparities in rural versus urban patients with pancreatic neuroendocrine tumors. It found that rural patients have shorter PNET survival.

So why might this be?

The answers are complex, and involve many intertwining factors. We'll explore them throughout this episode, but it's important to keep in mind that none of them exist separate from the others.

First, we'll talk about some of the things that might impact diagnosis.

Diagnosis is a famously frustrating process for NET patients. Tumors often go undiagnosed for years, then misdiagnosed for a long period after that. But this can be worse for people who don't live in urban settings: [one study found that patients from rural areas were likely to be diagnosed at a more advanced stage of disease.](#)

Part of this may be because not all primary care physicians are well-versed in an uncommon disease like NENs.

***Hallet:** So in specialized center, you will have people that are maybe more knowledgeable in a disease, more specialized by the fact that that's what they treat. And then when you are in, less specialized center, more local centers, you have people that have to treat everything that comes to them. So they have a very broad general knowledge, but when it comes to time to see very specific diseases, they may not know about it.*

This means that sometimes, NENs may not be considered and patients may not undergo testing right away.

When it comes to testing, there may also be roadblocks. Local health facilities in rural places tend to not be as well-resourced as urban centers.

Hallet: *Sometimes it takes longer if you don't have all the specialized tests in-house. And some tests that are more challenging to get, depending where you are, can be, like, angiogram to see inside the small intestine for those who need that. And then gallium or copper or, you know, other somatostatin receptor PET scans, can be more challenging to get. So you may not get the same complete and comprehensive assessment and understanding of the extent of disease.*

Without these advanced diagnostic tools, it can be challenging to figure out the most effective treatments.

In some cases, people may not even seek out medical care in the first place. When care is harder to access, people may not be aware of the options available to them. In addition, a lack of understanding of the healthcare system may make people less likely to pursue care.

Hallet: *At a patient level, there's also sometimes differences in health literacy and understanding when people need to go and seek care or, advocating for themselves in the decision-making process or participating in the decision-making process. And so that can make differences as well.*

Soares: *One of the things that was really interesting to me to learn is that there is almost like a fear of seeking attention from the healthcare team. Because many of them, especially the older generations, associated with seeking care to end up being in the hospital and then many times having bad outcomes.*

You know, it's the opposite of me, right? I mean, I grew up in a big city where I have access to care. So, oh, if I, if I don't feel well, I can even call my primary care, go to acute care, have been taking care, and then I'm better. But if I didn't have this access, I would have to be really, really sick to go. And then I will have perhaps passed the timing that something very substantial can have done to improve my care. And then the association indirectly is that, if you end up seeing a doctor, you're in bad shape and that can be done for you.

Gene Matthews: *My name is Gene Matthews. I live in St. George, Utah, and my diagnosis is a midgut neuroendocrine tumor.*

Well, I, uh, in 2013, went to the doctor with a bit of unusual stomach ache. In the process of diagnosing a gallbladder issue, they noticed a tumor on my liver. I had to gallbladder out and they biopsied the tumor at that time.

And of course, since they had the pathology in front of a microscope, they could tell precisely what it was. And so they proceeded to remove the gallbladder, but then scheduled me for surgery to try to find the primary tumor.

I felt very blessed that I had a surgeon here in little old St. George that had done enough research that he knew that there was a primary tumor that needed to be addressed. And he did that.

I thought it was very fortunate because this was 2013. And at that time, most doctors had never, ever heard of neuroendocrine. And here this guy, very professionally went in and attacked the problem.

For a while, I took the somatostatin medications like octreotide, lanreotide for about 3 years. And at that point, PRRT had just come off clinical trial and it was being done at Huntsman Cancer Hospital in Salt Lake City.

So I went up there, for, I believe it's about eight months, because you have four treatments scheduled eight weeks apart. And so I had PRRT. That lasted until May of 2019.

Then I basically went on just kind of a follow-me regimen for several years. I think it was in 2021 that we started seeing some metastases in the liver, and so they started me on Cap Tem. I did not do well on that.

And, we then went back to the drawing board, so to speak, and ended up here in the last two or three years doing liver embolizations. Unfortunately my last, about nine months hasn't been as good.

I developed some pain in my abdominal area. Turns out it was a mesenteric mass that needed surgery. And I ended up going to Denver. And it was pretty serious surgery and I'm still recovering from that.

St. George is in the very southernmost part of the state right on the highway to Las Vegas. We have about 200,000 residents in the county. I'm not probably as remote as many of your listeners may be in that we have a hospital, about 300 bed hospital, here in St. George, complete with the cancer center.

So I've been able to use a oncologist here. Unfortunately, he only sees patients once a week, but, anyway, I was able to go with him. And after I started getting treated, they employed a specialist in Salt Lake City by the name of Dr. Mark Lewis, who's quite prominent in the neuroendocrine community.

My doctor and Dr. Lewis easily spoke together, so Dr. Lewis supported my diagnosis. He and my doctor kind of have their own little tumor board for neuroendocrine patients. And so that's worked out well.

I've heard that my doctor has maybe as many as a dozen NET patients now.

There is no support group. I'm a member of the Salt Lake support group, but quite honestly, I've never gone to one of their meetings cause it's just too far to travel. You know, a one hour flight to Salt Lake costs me \$400. So I tend to drive, and that takes me five hours.

For the most part, I've been pretty lucky. And played golf three, four days a week, so, that's all been pretty good. Uh, the last few months have been a little frustrating, but it was mostly recovery from the surgery, which unfortunately I got an infection, ended up back in the hospital in St. George.

But I did play nine holes here earlier this week, and hope to get back to 18 here shortly.

Once someone living in a rural area does eventually get a diagnosis, there are new challenges to consider when it comes

to treatment. These challenges can impact what kinds of therapies a patient receives, and when.

Like we said earlier, rural places are characterized by low population density and sparse resources. This makes distance one of the biggest barriers to accessing medical care.

This goes for any kind of medical care -- but it gets more complicated when it comes to a disease like NENs, where it's important to seek specialized care from a team of experts.

Soares: *Many of the treatments of neuroendocrine cancer are related to surgeries and embolization procedures or interventional procedures, radiology procedures, and you have to be in a center where you have the expertise to receive these treatments.*

For example, you probably are not going to have the resection of your pancreatic tumor in a very rural hospital, where you might not even have an ICU to be monitored post-surgery.

Hallet: *In terms of treatment offering or, you know, troubleshooting the different options, neuroendocrine is a world where we have lots of treatment options, but we don't know best how to sequence them. So it is highly individualized to each patient. And so it's not something where you can just follow a clear-cut algorithm.*

Soares: *And that's why leveraging the expertise of a center that has high-volume expertise is so important. And many times these high-volume centers are situated in big cities, or at least, universities. So that is not necessarily in a very rural population, right? So the patients in the rural population have to drive.*

Sometimes, patients have to travel hundreds of miles for their care. And this can go beyond one-time trips for procedures like surgery or embolization: some treatments require regular visits to a cancer center.

For example, many patients with NETs will qualify for somatostatin analog injections, like octreotide or lanreotide. Currently, patients in the U.S. can't self-administer the monthly shots.

Soares: *So they have to go to a center. Then some of these patients might live two, two to three hours away from a cancer center. So even to get their monthly injection, it might require them to travel two to three hours.*

For other treatments, like PRRT, it can get even more complicated. This treatment is an important part of NET care, and it has to be done in a specialized setting. It is usually administered 4 times, each 2-3 months apart.

Soares: *Thankfully, we are having many more specialized places in the U.S. But then when you look at the map, you see like in the northeast, it's a concentration of places that can do that. And then you go to the mountain west, and you have maybe now three places. We have University of Utah, we have one place in Montana that just recently started doing [it], and we have one place in Idaho, and that's it.*

And we're talking about a huge amount of territory that is only being covered by perhaps three centers that can do the treatment and patients have to travel for that. So you say, okay, they'll just travel, to get their treatment. It's not that easy because to travel to some of these places, you can take like six to eight hours to get there.

These distances can be further complicated by uncontrollable factors like weather conditions. Bad weather can impact which treatments a patient might be able to get.

Soares: *How do you do that in the winter? When you have very limited roads that are clear, right, from the snow storms and so forth? So it can affect and delay your care because we're like, okay, we won't be able to start your treatment until the winter is over because you cannot get to our cancer center until later because the weather is very unpredictable.*

When we do PRRT, there's- it's not something that if we don't take the dosing one day that typically we can easily do the next day, there's a whole logistics involved. There are times that because of the weather, the drug doesn't get to us because they got stuck in a snowstorm.

So yeah, I mean, I had patients that I have decided on starting a pill before the PRRT, just because the patients wouldn't be able to get to me during the winter. And then I was like, okay, in the meantime, we will be doing a pill and then I can just send it to your pharmacy.

One piece of good news is that there are more NEN experts in the country than ever before, and modern technology has made them much easier to find. So if you are able to travel, finding proper care away from home has never been easier.

Serra Kefeli: *My name is Serra Kefeli. My diagnosis is small intestine neuroendocrine tumor with metastasis to the liver. It is grade one, stage four.*

Currently I work from home. I work for a hedge fund. I'm in the trading operations department. I live with my fiancée, Quentin, in Whitsett, North Carolina. Whitsett has 593 people, according to Google. That's the population. But it doesn't feel like that. You know, you can drive like 20 minutes to Greensboro and it's really not that bad. Like I think Greensboro has obviously thousands of people.

And the closest big city, I would say, is Raleigh. And so that's where I actually see the neuroendocrine specialist. So it's about an hour to get there. And then an hour back.

I moved down to North Carolina from New York City about a year ago. And I have a uterine fibroid and, unfortunately, I didn't really prioritize my health too well in New York, but when I came down here, you know, I noticed, okay, let me take things into action and see what's going on with this fibroid, because I knew I had it for many years. And so I saw a specialist at Duke University hospital, and he said, 'Okay, let's do an MRI, let's see, where the blood flow is in this fibroid so we can safely take it out.'

And with that he saw an enlarged lymph node. And so they said, 'Okay, let's do a PET scan.' And so, unfortunately, the PET scan had revealed a metastasis to my liver.

I had good thoughts going into the scan because I didn't think there was anything wrong with me, but, uh, quite shocking to get the results. Um, that scan happened in April 2024, so I was very recently diagnosed.

After I got the liver biopsy done and the diagnosis came through, luckily I was able to see a specialist very quickly at Duke. From there I really wanted to get a few out there opinions. Because, you know, this is sort of a rare cancer. I also have carcinoid syndrome. So I went to MD Anderson in Houston, Texas. They confirmed what I have as well. And also I went to Mount Sinai in New York and they confirmed the exact same thing. So it was comforting to know everyone was on like the same page.

The doctor at Mount Sinai in New York had told me I probably had this for a decade and didn't know about it. That's why there has been so much spread.

You know, it's definitely like a new perspective on life, and luckily I have a really great support system and, you know, I feel great every day. Especially after starting the lanreotide treatments, which is a monthly hormonal injection. And I feel totally, honestly, back to normal. I don't even feel like I've, you know, stage four neuroendocrine cancer.

But I do have my highs and lows. There are days where I feel like - I'm 32 - I feel like, 'Oh, am I going to make it to my retirement age? And live a long life with my fiance?' But I really try not to focus on that too much and really try to make the best out of every day and every moment.

And like I said, my work is remote and I was very open and honest with work about what's going on. I'm glad I told them, to get their work from home opportunity and I have unlimited days off, so, if I have to take a doctor appointment, like they know what's going on

And you know, I'm born and raised in Brooklyn and I'm from the city, so I have a bunch of family over there and in New Jersey. So that's where I actually do my follow ups now. So my three to three and six month scans as I do it in New York. And it's very comforting for me.

I always make something out of it. I see my family, I see my friends. You know, I stay with my grandma, I stay with my aunt in Brooklyn and it's about 45 minutes to an hour train ride to the specialist who's in Manhattan. It's nice to kind of take the train and relax, be a little comfortable on transportation like that.

Because, you know, these are stressful appointments and like driving an hour to Duke and then driving an hour back, it's, you know - and I usually go by myself, my fiance has work and, you know, these appointments are during the day. So, unfortunately, he can't really go with me. And so it's just nice not having to focus so much on, 'Oh, I had a stressful appointment, now I have to drive a long ways back.' So it is nice having those other transportation options in New York.

And, you know, I really- my heart goes out to people who are struggling with this, but if there's a way that they can make it work somehow, you know, I really would encourage people to really get the specialist and right attention that they can because this really is a specialized type of cancer.

And there are so many different avenues, so many different treatment options and plans that people can do. And so it's just really important for them to, you know, seek out that care if they can.

Of course, not everyone has the resources for frequent travel.

Socioeconomic status plays a key role in medical outcomes. And in the United States, rural poverty rates are higher than urban ones -- this is one of the factors that contributes to inferior outcomes for rural patients.

Travel is expensive, and there are added financial challenges like missing days of work and securing childcare. These all become more complicated if you are working with fewer resources.

Soares: *If you're thinking about a patient that is in the workforce and is young, there's the issue with losing the job. And also having care if the patient has children and*

that's very complicated. I have many patients who have brought their kids here during their treatment.

And for my elderly patients, they are on a very limited income, let's say just for the Social Security, the amount of money that they get is very limited.

People with low incomes are also more likely to be Medicaid recipients or uninsured. This can further complicate the financial picture.

Soares: *And then they will take them money to drive here. That's gas money. There's food money. There is housing money. And that is, it is all important. And then if the patients have co payments, for their, cost of their medications, that adds on, you know, a 10 co payment for you might be very affordable, but if someone that is living on \$1,500 per month and had 15 drugs with 10 co payments each, and then they have to pay the rent, their food, their gas, that's a lot, right?*

(music)

Soares: *You know, there's someone that I talk about getting to a trial. He was working on the border between Nevada and Utah. And he was, sort of a construction worker, and he was working paid by the day, so he shows up to work, he gets paid. He doesn't show up to work, he doesn't get paid.*

And he will qualify for one of our trials, which I thought was important for him because he had a resection of his tumor. But, he, we, we did some of the process for the trial. And then he called me, and he said, 'You know what, I cannot come because I need to pay the bills and I need to get this money for the day to be able to pay the food for my little kids.'

That just crushed me, right? That just like, oh my God, you have to- you have to decide between your care, versus putting food on the table for your little kids. That's just like...

So, thankfully, this was a situation where, if he didn't go on the clinical trial, the standard of care would be

observation. So, it was not like he was being deprived of getting any treatments, but he hasn't come back to me most likely because of the challenges of coming here.

Throughout this episode, we've talked through a number of different factors that impact care for NEN patients who live in rural areas -- whether that's education, culture, distance, or resources. But like we mentioned before, none of these are separate from each other.

Hallet: *Really they happen often together and they compound each other. And so you can see how that can impact whether somebody notices that they have symptoms or a problem. Number two, seek care or assessment. Whether they receive that assessment, what that assessment is, whether the right thing is identified, and then whether the right care is thought of, and if the correct referrals are made.*

And then once the referrals are made, whether people are able to attend those new consultations and if treatments are suggested, whether they're able to implement those treatments. So it's a lot of different layers that come into play and it will pan out differently for every person.

This may sound like a large, complex web of challenges, but there is a lot of work being done to remove barriers and increase access.

On the patient level, one tool that has been helpful in bridging some of these gaps is telehealth.

Soares: *If I hear that a patient is coming from far away, I actually try to convert as much as possible, and as much as the medical license and the regular-state regulations allow me, to have a virtual visit to kind of coordinate the patient's care. And understand the patient's needs before they come to see me in person.*

This is one of the silver linings of the COVID-19 pandemic -- even though rural internet access and cell phone coverage can be spotty, telehealth can be a great way to save a patient's time and resources.

Hallet: And then the other piece is trying to break down some of the social and financial barriers for patients to get access to those specialized centers and those networks. So whether it's like sponsoring travel, including vouchers for the day of work that you have missed, the day of work that your partner might've missed, or it's childcare, and facilitating these things.

But it's not just about bridging these gaps -- on the physician level, it may be possible to organize care in such a way that the gaps themselves become smaller.

Hallet: There's this idea that regionalized care or specialized care is care that is necessarily away from patients. But I think that we can envision care networks where specialized care doesn't have to be away from patients.

Both Dr. Hallet and Dr. Soares emphasize education and collaboration as the means to accomplish this.

Hallet: Education, to me, comes with awareness. It's about healthcare providers, at all levels, being aware of what neuroendocrine tumors are and just think about it. You know, there is this saying in a lot of neuroendocrine communities, if you don't think about it, you cannot detect it.

Soares: It's not about only the provider ordering the right test it's about the right test being done properly.

You know, a CT scan by itself doesn't solve the problem. You have to know how to do the CT scan. To do that, you have to order the CT scan properly with the proper timing of the contrast and the radiologist has to recognize that and accept that and make sure that the timing of the contrast is done properly.

So there's so many levels of where education needs to be done. It's not only about the person in front of the patient.

Hallet: So that's the first part. And then collaboration and building care networks. I don't think it is realistic to think that we're going to have neuroendocrine

specialists in every local hospital or healthcare institution. Just because even if they're more common now, it's still not something that is very common.

So there's always going to be specialized centers that are a little bit further away from patients. But that doesn't mean that we're not able to build systems that can bring that knowledge to the patients.

Through established partnerships, specialists can serve as resources for local healthcare providers.

Soares: *The partnership of the local providers in the rural communities, they really, truly feel they have access to specialists to ask questions in any form or shape. It's either from a phone call or tumor board or official visits, but I feel that's so important because if you don't have that support to guide the care that you are doing locally, then it becomes impossible to deliver the care that a patient deserves.*

Beverly O'Neill: *I'm Beverly O'Neill. I live in Moab, Utah. My diagnosis is carcinoid, and metastasis to the liver.*

The first clue was in 1987. In the middle of the night, I woke up and I had to go to the bathroom really bad, and I didn't make it. And I just, you know, lost it on the floor there. And, it was this kind of red, tarry- it was blood.

So, I went to work the next morning and I was feeling, you know, how when you stand up and you're anemic, you know, like my head was spinning. I felt terrible! So I took off from work and went to the- oh, by the way, I was living in Seattle, Washington at the time. And so, I went to the doctor and she took me over the emergency room immediately. She said, you- you've lost a lot of blood!

Anyway, they did a lot of testing, trying to figure out why I bled, where I was bleeding from, and they came up with nothing. So, the next year, 1988, it happened again. So again, more tests. Nothing showed up.

Then in 1989, it happened again. And this time they said, you know, this is the 10th pint of blood you've gotten in the, over the course of the three episodes. And we need to go in and figure out what's going on! So they knew it was in the midgut, but they had no idea what was causing it.

Well, anyway, long story short, that's where my primary was: in the ileum. And, there were a few lymph nodes they removed. They took the appendix out and the valve to the large and small intestine.

Anyway, they were shocked when they discovered it was, um, cancer! They, they just weren't expecting it. They being the doctors. And believe me, in 1989, they knew nothing. They've never seen it before there! And I'm talking Seattle and one of the hospitals there, okay?

So fast forward to 1996, they did a CAT scan and it showed that I had, uh, lesions in my liver. And so then I go on- and there was internet in 1996, but it wasn't what it is today, believe me. And so I went on and I found a support group actually, for this cancer on AOL in 1996. Because I wanted to find out what my options were.

Well, that led me to Dr. Richard Warner, and he was at Mount Sinai. He was a gastroenterologist there. So I contacted Dr. Warner and asked him, you know, what I should do, I sent him my records. And he recommended chemoembolization.

Then I got my doctor and hospital to agree to do that. And so there were three embolizations and then it followed up with 18 months of a systemic chemo. And then, they had the sandostatin, but at that point in time, 1996 now, it was a sub Q three times a day, if you can believe that.

So- but I did it! And, I can't remember exactly when the LAR, the long-acting, you know, every 28 day thing. It was like 97, maybe 98. I can't remember exactly when it came into being, but boy, what a game changer for me! And so, I maintained that for years.

Meanwhile, I met my husband and he was a commercial fisherman in Alaska. And he convinced me to come work with him, which I did. And we had a wonderful life, working in Alaska during the summer and we lived in Seattle.

And I was in an HMO in Seattle and at that time, because I wasn't on Medicare, they, approved me getting the LAR kits and taking them to Alaska with me and my husband would give me the injections.

That was awesome. Then I went on Medicare. Which was not portable, not portable at all. Everything had to be done in Seattle at the hospital.

So, I actually flew down from Alaska every 28 days to get my injection at the hospital in Seattle. That was a problem when you're in the fishing industry and you're out on the water. Anyway, we made it work.

And meanwhile, we had bought property in Utah and decided we wanted to retire here, so we'd come down here and I would fly up to Seattle to get my shots.

But anyway, we retired, we moved here, actually moved here in 2018, to Utah. Okay. And then I had my opportunity to change because there was no advantage plan available in Moab. Yay. And I got on the supplemental, which is so portable, so now we live in, in Moab. We moved here in 2018 and, uh, retired, just, 2022.

So now we're down here full time. Moab has- it's a town of about 5 to 6,000 people. And, there's a regional hospital here. It's a really nice little hospital. There's primary caregivers that work there. And a lot of specialists come in to provide care.

A lot of them come from Grand Junction, which is in Colorado, only 120 miles away. So they come over here and see patients and I was able to get an oncologist that would come over from Grand Junction once a month. And so I was able to meet with her.

Anyway, based on my history and everything, she decided to do a PET scan. So I did a PET scan. It showed that the

tumors had started to grow and there was activity again. Okay. So she suggested I go see Dr. Lewis, who is in Salt Lake City, and talk to him about getting the Lutathera treatment because I was a good candidate for that with my history and everything.

So I did that, and I just had my fourth Lutathera in January. And I've got an appointment next month for another PET scan to see the results of that. But I feel really good.

So living in rural Utah, there's places that I would- we would love to live in Utah, but they're like, I mean, I would have to, once a month, go like 200 miles to a hospital to get an injection.

Anyway, you've got to really look at that aspect. Fortunately, Moab has a hospital I can get my injections in, and if I need specialty care, it's only 120 miles away. Or I could go up to Salt Lake City, which is, you know, about a four hour drive. But anyway, you've got to really consider those things with this disease.

While specialists, local doctors, and care networks do everything they can to provide the best possible care, it remains true that accessing medical attention is more difficult for the millions of people who live in rural areas.

But patients have a lot of agency. Even when resources may be difficult to access, they are still there for patients. And there are lots of people who will do everything they can to help connect patients with the care they need. It's important to remember to advocate for what you feel is best for your situation.

Soares: *You say, 'Okay, I hear what you're telling me. Is there anything that can be done for me? What else? Which other tests should be done? Should I be seeing someone else? Should we work in partnership with someone else?'*

Ask questions. Folks from the rural- very nice folks that tend to be very polite and tend to just accept what is being told. You know, but sometimes, especially when you're dealing with a rare disease, you have to shake it a little bit and you have to ask questions.

And don't be shy. Don't feel like you're going to be annoying or difficult, or labeled as challenging, because you are asking questions. It's our job to help you to navigate your care.

Hallet: *And to me, at the end of the day, access doesn't necessarily mean that everybody receives every single treatment that is proposed to them. Access is about opportunity.*

So not all treatments are right for all patients. For medical reasons, sometimes for personal reasons, doesn't align with wishes and values. And wishes and values include sometimes having to travel regularly for treatments is something people may not want to go through.

But at the very least, everybody should have an opportunity for care. And an opportunity for care means you need to meet with somebody who can discuss that care, and explain things. And then after that, people can make their decision to be based on a million different considerations. But to me, access is opportunity for care.

Thanks for listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF.

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Episode 38:
Rural care
Transcript

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