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I'm Laran Hyder, from the Neuroendocrine Tumor Research Foundation, and this is a special episode of NETWise.

A lot has changed for all of us lately, and we've been recording new NETWise episodes in a very different way. I used to record these episodes in a studio in New York, in the same room with our producer, David, who was operating the recording equipment and making sure I sounded good. Now, instead, I'm home in my living room in Boston, with a microphone and a portable recorder I learned to set up myself, and David listening in over Zoom.

David: *"Hello! You're doing great, by the way"*

It's a big change, and one that took some getting used to. But all of us are making changes in our daily lives to ensure we are safe and healthy despite a world-wide pandemic. A big part of these changes is doing things virtually from home.

This is definitely true in health care, where in-person appointments with your health care team are now being converted

to online or telephone visits via telemedicine. Telemedicine experienced great growth in years prior to the COVID-19 pandemic. In previous years, the percentage of health care systems offering virtual appointments increased from 39% in 2017 to more than 64% in 2019. And now, of course, with large numbers of people all over the country following stay-at-home orders or social distancing, emergency orders have opened up tons of new opportunities for telemedicine. And many clinical practices are offering remote visits to some of their patients.

So, what does this mean for NET care in 2020? How are doctors and patients navigating this new world of virtual patient care? Here's Dr. Heloisa Soares, an oncologist at the Huntsman Cancer Center at the University of Utah:

Soares: *"You know, this is a learning process to all of us. I have to admit that prior to the COVID-19 pandemic, I had really never explored the idea of telemedicine with my patients. So that has been a paradigm shift, starting in probably mid-March, when we encouraged the patients when possible to convert their in-person visits to telemedicine visits."*

There was some trepidation from both doctors and patients about converting in-person visits to virtual appointments. Here's Julie Mebane, a PNet patient who is a member of the NETRF Board of Directors.

Mebane: *"Well, I've always felt that there's no substitute for meeting somebody in person. I think in-person contact*

is so important—you feel like you really get to know somebody better. You can read their body language and look at them in the eyes and really get a sense for what they're saying in a different way than looking at somebody's picture on a screen. That was my bias going into it. So, I just didn't think it would be very effective, frankly.

But I was surprised. I didn't feel like it was ineffective at all. And I did feel like I got to actually exchange ideas and meet the doctors. And I thought it was fine."

As we are all adjusting to a new normal, more and more NET patients are embracing the use of telemedicine. Here's Katie Baker, a BSN registered nurse, who works with Dr. Soares at Huntsman:

Baker: *"We actually have found in the beginning, like with any change, people are hesitant, but oftentimes with, you know, change in practice, all of our patients now in the last couple of weeks are extremely positive. And every time we've had a virtual, you know, interaction or have been able to practice or met with the patient, there's always a resounding 'this was amazing!' 'This is the way of the future'. Everyone has been extremely adaptive and has done an amazing job of making it work*

And truly people are actually, I think sometimes happier with this visit versus, like, an office visit, because there is no waiting room, you know. They're able to stay at home in their pajamas, you know, for example, and then are

able to have that contact with their physician, you know, undivided attention."

Mebane: *"so, I did not have to travel. I didn't have to go into a big, scary looking medical building. Undoubtedly my heart rate probably was lower in my own house than in an institution somewhere, so yeah, it was much more comfortable."*

Also, many are finding that these virtual visits can actually feel more personal and intimate than a standard office visit, because it's kind of like welcoming the doctor into your home, where you might feel more comfortable and confident.

Mebane: *"well, I normally go to institutions where they're teaching hospitals, doctors tend to come in sometimes accompanied by others, and it's almost a group visit. I, in these appointments have found that they tend to be one on one, and that's a different kind of connection too. And I think it's a better connection sometimes- just patient to doctor. There's no crowd."*

Soares: *"I have a sense of their wellbeing. I also sometimes ask them to introduce to the other family members that are either in the same room as them, or have joined the meeting from their own locations, because we, you know, can go both ways. Sometimes I tell them, 'oh, I love your home. Let me see a little bit more'. And then it feels like*

so much more, is greater, that even though we are in distant places, in different places, it feels very warm and connected."

Another advantage to these virtual appointments is the ability to include family members and loved ones, even if they live far away.

Baker: *"So then we'll call the family members while Dr. Soares is beginning the meeting with the patient and they can join sometimes from States away, you know, which is awesome."*

The ability to include others in a telemedicine visit is especially nice, because many hospitals are now limiting in-person appointments to patients only.

Soares: *"Yes, so right now we still are using the no visitor policy. So, if someone comes alone, they, you know, they feel sometimes lost and sometimes it's not the same to just have them, the care of the loved ones or the caregivers in the phone. And using the video conferencing, we can see everybody, and we can interact much better. So, if family members want to be involved that is a very good strategy to do so."*

Moving some patient visits to telemedicine also reduces the number of patients who are in the doctor's office at any one time, making it safer and easier to socially distance.

This does start, though, with learning to use telemedicine platforms. Not everyone is familiar with the technology involved in a virtual meeting, so clinicians and their teams are working hard to ensure their patients are comfortable and confident when attending a telemedicine appointment.

Baker: "I joke all the time with Dr. Soares that I should maybe, like, have a side job of Zoom technical support (laughs). I find that, you know, with time at the beginning, it was a learning curve for myself and a learning curve for the patients. So, we will always appreciate their patience and their ability to learn and work with us, but now it's become quite second nature. Truly, a lot of these applications are very user friendly, which is awesome. The technology, I mean, we have a wide variety of age ranges that we, of our patient population, and we've had patients as young as you know, in their twenties their mid-twenties, and then patients as old as, you know, almost 90-89, 90- and they've all been able to master the skill, which I think is incredible."

For the Huntsman Center team, this starts the week before the first online appointment, with a series of prep calls to make sure the patient has the necessary technology and knows how to use it.

Baker: "So, the week prior, so, for example, we have clinic on Mondays and Tuesdays, so, say Wednesday through Friday, we will call the patients and we will ask about their use of technology and their comfort level. We will then invite

them using our own technology at work via iPad or cell phone, to invite them to a meeting, to practice with them, to troubleshoot, to see them face to face, to encourage them over the phone, to you know, kind of reassure them that everything, you know, that's how it's going to be. And then we give them encouragement that we'll call them the following week on the date of their appointment, about five to ten minutes prior to, send them an email link with an invitation to whatever platform or application we're using or give them a call with the meeting ID and password."

Soares: *"It shouldn't be something that the patients will do for the first time when they have the doctor's appointments, because they might be so nervous, and things might not work well. So, practicing the week before where there's no pressure is a great strategy. If they have family members that are living with them and a little bit more tech savvy, then, you know, asking for their help. For example, I have patients that live with their kids or grandkids, and then the grandkids was able to help the patient in figuring out why the sound or the microphone wasn't working and things like that, you know. And if everything fails, you know, what we do is, I pick up the phone and have an initial phone conversation, and then depending on the phone conversation and how I think the patient understands things or not, I'll bring them to the clinic."*

To get the most out of a telemedicine appointment, it's also important for the patient to prepare.

Mebane: *"Well, I think one of the main things a patient can do to make sure it's an effective appointment is to have the technology, make sure you have the right tools to do this with. I've also tried to do appointments on FaceTime on my little iPhone (laughs). It's not the same as having the doctor right there on a nice size computer screen, having a good internet connection, having things lined up so that you're comfortable. You have your documents handy when you know, your health records handy when you're on the phone, you have your list of questions handy."*

Soares: *"I think it's very important to prep in terms of having a very clear history to provide to their physicians, because that's something that sometimes we don't get a sense. And if someone is prepping and can write things down, even potentially a fax or email to us prior to the visit, that's great. So, really paying attention to the prior history, prior to diagnosis is going to be super helpful for NET patients, making sure that we have all the records and documenting the symptoms and seeing any symptoms that are associated with their diet or associated with any of the medication that they are taking. This is something that is extremely helpful, and if they can email it or send it to their physicians prior to the visit, it will be extremely helpful."*

But of course, not all health care visits can be done remotely, so an important part of this process is a thorough screening to determine which visits are most appropriate for telemedicine.

Soares: *"There's appropriate patient for the virtual visits, so that's why it's so important for us to triage before the appointment. Number one, we need to make sure that the patient has the proper technology to do so. Number two, we need to make sure that the patient doesn't have any significant acute issues that will not be appropriate to be addressed in a telemedicine visit.*

Patients that are coming just to review scans and don't have any clinical complaints, meaning they don't have any symptoms that I need to address, they are patients that are extremely appropriate for a teleconference visit. Patients that was just recently diagnosed and they want to explore a second opinion, I think it's also... most of the cases is very appropriate for a videoconference, telemedicine type of visit. Patients that have a lot of symptoms, such as, you know, abdominal pain, shortness of breath, dizziness, these patients are probably not the best candidates for telemedicine because there's a very good chance that I will need them to, get blood work done. I also need to examine these patients right. If someone complains about abdominal pain, it's part of my job as a physician to examine their belly and that's not something that I can do properly through telemedicine. And also, if someone is complains that is dizzy, I need to make sure that I have a blood pressure and a pulse. So, when someone is extremely

symptomatic, I do not think that's an appropriate ways to evaluate this patient.

I also don't think it's appropriate way when we're having end of life conversations, because, you know, you can imagine I'm giving this patients very bad news and that's a horrible way to do that, through telemedicine. Having said that, especially when the peak of COVID-19 was here, we had to do some of these, and I can tell you that it was an awful experience for me, so I can imagine it was an awful experience to the patients as well. Unfortunately, we didn't have a way around that. Now that many states are opening up, I am opting to bring these patients in for this type of conversations.

So, these are the situations that I don't feel they are appropriate. But again, for patients that are have no symptoms and this is just a touch basis situation and review of their scans, that's when I think it works."

The increase in telemedicine use over the past few months is creating new opportunities for NET patients. Before the COVID-19 pandemic, the widespread use of telemedicine was limited by insurance reimbursement rates, interstate licensing and practice issues. Since the start of the pandemic, federal policy makers in the United States have enacted temporary changes to enable greater access to telemedicine. Increased telemedicine use has resulted in greater access to health care. This is especially true in both rural and urban communities where patients can experience greater wait times for appointment's or a lack of

specialists needed for patients care. This is especially true in the NET community.

Many NET patients travel great distances for their care. Increased access to telemedicine is allowing some NET patients to get their lab tests and scans done closer to home, then review the results remotely with their care team.

In previous episodes of NETwise we have emphasized the incredible benefits of recruiting an experienced NET specialist to be part of your health care team. We know that NETs can be tricky to diagnose, treat, and monitor. That's why we encourage people to partner with a NET specialist or even seek different opinions to find the best NET cancer care. But we understand that working with a NET specialist or traveling to faraway appointments is not an option for everyone. However, virtual appointments via telemedicine are now enabling NET patients across the country to reach out to NET specialists.

Mebane: *"There is one good thing that has come of this pandemic for patients is that we are able to see doctors almost anywhere right now. That's an amazing opportunity that didn't exist apparently, before this all happened.*

I have a local oncologist, who's wonderful, but I, my NET, my neuroendocrine cancer specialist has been in another part of the state ever since I was diagnosed. We have had the discussion about possibly getting my testing done either close to home, or maybe at the institution that I'm going to be seen at, and then coming home to hear the

results a few days later, rather than trying to stick around after traveling and waiting to meet with the doctor in person. That's a possibility.

I think in the future, if I need to get a second opinion on something too, I would definitely consider a telemedicine visit. Again, you don't have to go to the institution itself when you're seeking a second opinion. You can have your electronic records sent there and meet with the doctor using modern technology on a computer screen. It's a pretty good way to avoid a trip to possibly, you know, another part of the country when you really don't feel like traveling."

Baker: *"I can't tell you how many patients from Wyoming, Nevada, Idaho, you know, even California, they've reached out and been able to do second opinions and just firsthand, they've had just incredible experiences that have been incredibly grateful for the opportunity to meet with a specialist."*

Soares: *"Now that we are allowed to do telemedicine with other States because of some of these emergency rulings that allow us to practice in a different state, I have had increasing some of my second opinions, because some of my, that my colleagues in the community say, 'Hey, I thought that will be too much from a patient should travel eight hours to see you, but now that you're doing telemedicine, would you mind talking to the patient and giving your opinion about her or his case?' And I was like,*

'Absolutely! I'll be happy to do so.' So I do my consultation with the patient and then typically I follow up with a call to my colleague and say, 'Hey, this is how I think we should, you know, continue to work and improve the care of this patient and coordinate scans and all the things that are related to patient care.'

I'd love to continue to give opinions via telemedicine, particularly for patients that live far and have a community doctor that will appreciate having a second set of eyes."

Of course, this will only continue so long as these temporary changes are in effect. At the time of this recording on June 25, 2020, eased access to telemedicine is still ongoing, however, accessibility guidelines may change, so we encourage you to check with your insurance provider before requesting or having any telemedicine appointments.

Soares: *"As this is phasing out and the States are not allowing that anymore, I will either have to apply individually to either states to be able to continue with that, or request that patients to call me in person. So, I think is our job now as patient advocates to advocate for a change in how this can be done for the future. Because I think especially for rare diseases such as neuroendocrine tumors, where specialized expertise is so important, it will be amazing to have neuroendocrine tumor experts as a second opinion and a backup for patients that live far away."*

The on-going pandemic is challenging all of us in unique ways. Just a few months ago no one could have ever predicted the extent of COVID-19's effect on society. The silver lining in all of this, though, might be the increased use of telemedicine.

Mebane: *"I'd love to think that this is going to stick. I think for neuroendocrine cancer patients, especially, it would be an enormously helpful development for this to be an option. There are a lot of people who are dealing with disease like this, that's a rare disease, they might not live someplace where there are specialists and this would give them the ability to consult with doctors in all sorts of big cities and clinics that they might not have access to, and do it in an affordable way.*

See, normally, until now, I think everybody's had to travel and spend huge amounts of money getting second opinions or checking in with a specialist in NET cancer. That's hard to do. And so, if insurance companies will get behind this, and the doctors are behind it, I think the patients would embrace it. Again, I don't think it will end in person visits by any means for a lot of reasons, but I think to be able to do this occasionally when the circumstances are appropriate, it would give patients a lot of freedom and it would really help patients with rare cancers."

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My name is Laran Hyder. I'm the Director of Education and Outreach for the Neuroendocrine Tumor Research Foundation and the Executive Producer of this series. It was produced by David Hoffman of CitizenRacecar.

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