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Hi everyone, I'm Laran Hyder, Director of Education and Outreach at the Neuroendocrine Tumor Research Foundation. In this special episode of NETwise, we're going to talk about the COVID-19 virus. As a NET patient, you may have additional risk for serious illness from COVID-19, so we want to share some tips for avoiding infection, managing your NETs treatment, and staying mentally healthy during this challenging time.

I'm going to share current advice about living with NETs during this crisis, as of when this podcast was recorded on April 7, but as you know, the situation is changing rapidly. Make sure you stay up to date with your local and national health authorities and your NETs care team for the latest information. The NET Research Foundation has an entire section of our website dedicated to up to date COVID-19 information, as well as NET-specific resources. You can find that information at [netrf.org](https://netrf.org) and on our social media pages. We'll put links to all of those in the show notes.

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A lot of people, especially those with NETs, want to know more about their potential risk for serious illness from COVID-19. The U.S. Centers for Disease Control says people 65 years or older, and those living in nursing homes or long-term care facilities, may have a higher chance of complications from the disease. The National Cancer Institute says adults and children with serious chronic health conditions, including cancer, may be at higher risk of developing more serious complications from contagious illnesses such as COVID-19.

Here's Dr. Mark Lewis, Director of Gastrointestinal Oncology at Intermountain Healthcare, a system of hospitals in Utah and Idaho. He's also a NET patient. We took these excerpts from a webinar with Dr. Lewis and NETRF CEO Elyse Gellerman. You can find a link to their complete conversation in the show notes.

**Lewis:** *"The first group that might come to mind at higher risk would be patients with lung or bronchial NETs.*

*However, the virus descending to that part of the lung has a very specific binding point to something called the ACE2 receptor, and it's really not clear that patients with lung NETs would be at any higher risk for that binding than anybody else. I will say, however, that any patient that's on everolimus, which can include patients with lung NETs or other NET sites, they're potentially at risk for pneumonitis. So they might have an existing lung defect, if you will, that puts them at higher risk not necessarily for the virus but for respiratory complications."*

The CDC also lists the following conditions as increased risk factors for complications from COVID-19, many of which are problems that often occur alongside NETs: liver disease, including active liver metastases and decreased liver function due to surgery, diabetes, chronic kidney disease or any other kidney condition requiring dialysis, serious heart conditions, moderate to severe asthma, severe obesity, or having a body mass index of 40 or higher, and a compromised immune system.

On that last point, some NET treatments can compromise your immune system, weakening your body's ability to fight off illness. One such treatment is chemotherapy. This includes the Cap/Tem combination often used to treat NETs. Another is any treatment involving radiation, including radioembolizations and PRRT.

While you are undergoing these treatments, there may be times in your treatment cycle that you are at an increased risk of infection from any respiratory illness, including COVID-19.

**Lewis:** *"So chemo and PRRT are very different in how they impact in immune system and how quickly. So with most chemo, we talk about cycles and the reason that we cycle most chemo is to allow recovery of the immune system. So some treatments, and I'm thinking here about, say, platinum-based chemotherapy for high grade NETs, or neuroendocrine carcinomas, I should say, that can have a very acute drop in immunity. So for instance, if I give someone platinum-based chemo this week, and will typically be cycling it in three weeks, what second week when they're*

*off treatment may actually be the low point in their immune system. So they hit kind of a trough, and either on their own or with assistance from us through growth factors they come out from the trough, and then crest again just in time to do the chemo again three weeks later. So that's an example of chemo and how the ebb and flow of the immune system can happen between and after cycles.*

*PRRT is a bit of a different animal. We know that just under 10% of patients undergoing PRRT will develop low lymphocyte counts, but that can be quite latent. The effect on the bone marrow can also be very long lasting. So the only way to know that is to have your blood count tracked during and after PRRT."*

How do you know if your immune system is compromised? Ask your doctors – they should be able to give you a clear sense of where you are in your treatment regimen and what additional risks might make it even more important to protect yourself from exposure to COVID-19.

Some people with NETs have had their spleen surgically removed. Without a spleen, individuals can be immunocompromised because of a lessened ability to fight certain bacterial infections. However, there is no current evidence having no spleen or having a spleen that isn't working properly can reduce your ability to fight off a viral infection like COVID-19. Regardless, all precautions should be taken to prevent any type of infection.

Until this crisis has passed, our medical system is going to be under a great deal of strain – so reach out to your care providers whenever you feel you need to, but be prepared to be patient in waiting for a response. Be prepared with information and questions in advance to help you make the most of the time you do get with your care team. Write down your questions in order of importance, and don't leave out something you've noticed because you think it will be considered silly, it may turn out to be important. If you haven't already, it's a very good idea to start keeping a log of symptoms and side effects of medication, noting down when they occur, how severely, and how long, so you can convey that information to your doctor as clearly and efficiently as possible.

Visiting many hospitals and other care systems will be different during this crisis. Some entrances may be closed. Open doors may be covered or tented to accommodate screening. Staff may ask about your health, symptoms, or check your body temperature before allowing you access to the building. Individuals with cough or cold symptoms may be directed to use different entrances or waiting rooms. Those with active respiratory symptoms may be asked to wear a mask. Signs and staff will ask you to practice good hand hygiene and cough etiquette. And there may be restrictions on where caregivers or visitors can go. Only patients may be allowed to enter patient care areas.

Before leaving home for a scheduled appointment, it's a good idea to check your health care provider's website so you can learn more about any changes in entrances, parking, or

visitation policies. To avoid touching things when you are there, bring your own pen or pencil, paper, snacks, and reading material from home.

Many health care providers are replacing in-person visits with technology. You may be asked to use advice telephone lines, patient portals, or online self-assessment tools. Telehealth uses video conferencing, internet streaming, and mobile apps to help patients and their health care providers communicate. Many states in the U.S. are adopting regulations to expand the use of telehealth because of COVID-19.

**Dr. Lewis:** *"The way we've been doing it here is, every week all the docs in my clinic – and I work in an eight-oncologist practice – we actually sort of triage our list of patients for the week, and we ask ourselves, 'who among these people is appropriate for a video visit?' And then we make the necessary arrangement that have to be set up. Now I do realize this is a new era where we're using technology simply because we have to – necessity being the mother of invention – but it is extremely rewarding. And I think... so the first thing I say to patients is go into it with an open mind, I think you might be presently surprised how much you can get out of an interaction. And I'll say this too, almost without exception, every single patient who I've done telehealth with has thanked me. And that's not, you know, me boasting, it's because right now they really don't want to come into the clinic, they don't want to put themselves at undue risk, and so they're actually thrilled*

*that we can have this connection and not have to have that person-to-person contact."*

Get familiar with these digital tools so you can use them to maintain communication with your care team. If you haven't yet registered to use your health care provider's patient portal, check their website for information. Some patient portals allow you to message your health care provider and request appointment changes or prescription refills. Again, what is available from your providers and covered by your insurance may vary.

In general, you may need to be more active and proactive in your care. We've assembled a few tools to help you feel more empowered in advocating for your needs with healthcare and insurance providers, you'll find links in the show notes for this episode.

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Be aware that medical resources, facilities, and bed space are limited, and are being triaged and redeployed around the country to prioritize combatting this virus. This may mean that imaging appointments and even surgeries and interventional radiology procedures will be delayed if your doctors feel it is safe to do so. This can be frustrating and scary, so speak about these concerns with your doctors and discuss why they feel it's safe to wait.

**Lewis:** *"There's competing threats here. There's the risk of the viral pandemic, and there's the risk of unopposed cancer. And right now, we're trying to balance both and not*

*put patients at excessive danger of virus, but also not allow their cancer to go unchecked.*

*As far as scans are concerned, again it depends on sort of the acuity or threat of the disease. If you're someone that's dealing with a high-grade neuroendocrine carcinoma with liver metastases, your scan is one thing; versus, say, someone that's on surveillance, perhaps, for a lower-grade NET... and again that's a discussion really to have with your oncologist.*

*Talking with oncologists around the country, I think many of us are perhaps carefully postponing routine surveillance scans by a couple of months, again to unburden the health care system, and also, and more importantly, to protect patients. If they don't have to come to our centers right now, they really shouldn't."*

Your doctors may even decide to delay medical treatments, such as infusions, that have to be administered at a hospital or infusion center, if they feel the risk of exposing you to COVID-19 at the facility where you receive care is greater than the risks of delaying treatment.

You may also want to ask your care team about home injections. Home injection programs, in which treatments are administered in the home by a trained nurse, are available for both Octreotide and Lanreotide from their manufacturers. We'll put contact information for both of these programs in the show notes for this episode.



**Lewis:** *"My understanding is that it is an option for highly trained nurses at the delivery of somatostatin analogues will then come to a patient's home. And this is potentially quite advantageous to keep them on track with their analogue schedule, but not have to bring one into an infusion center or a hospital."*

The decisions about how to proceed with treatment that takes place in multiple stages over a long period of time, like PRRT, must be made very carefully by you and your care team.

**Lewis:** *"I'd say that the calculus for starting PRRT now looks a little bit different, and we have to be pretty confident that the disease is threatening enough that we need to get PRRT started either for stability or, ideally, later on response. For people that have already started though, and again I'll say this is early April, and this might change, right now I'd be inclined to continue, really for two reasons. Number one, if we stop or postpone, in your example say, that fourth treatment, we're really getting away from our evidence base. We don't have a study that shows the outcome if you do, say, only three, only two, or only one. So it's always a little bit dangerous, and it happens in the real world all the time, but it's always a little bit concerning when you deviate from standard like that and we still don't know then how that effects, you know, outcomes."*

*And secondly, PRRT is an every two-month treatment, and so you don't have to bring the patient to your facility that often. And I know when they're here, it's a very intensive day of treatment, but I'll also point out it's a day where they're largely sequestered. So unlike, say, an infusion center where there may be dozens of other patients around you getting their infusions, PRRT is actually a very lonely day, because of the radiation.*

*So all that put together, my inclination so far has been if you're already on PRRT, we've been continuing. And again, that might look different a month from now, but right now that's what we're doing."*

Many of these considerations will also have to be based on the regional effects of COVID-19, which is much more disruptive right now in some parts of the country than in others.

**Lewis:** *"Here in Utah so far, we've been fortunate that we have the staffing still to continue our routine nuclear medicine procedures. Presumably, in hospitals in New York right now where it's all hands-on-deck, they almost certainly would not be staffing or bandwidth."*

Since every patient's situation is different, decisions about treatment during COVID-19 should be individualized. Talk to your health care provider about your symptoms, treatment history, and other chronic conditions to see what makes the most sense for you right now. See if there are alternative therapies to consider. Explore the pros and cons of all your options. Then,

think about what is most important to you. Through open dialogue with your care team, you can come to a decision that best suits your needs and concerns.

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When it comes to exposure to this virus, there are a lot of things we all should be doing to protect ourselves.

Some of the most important things you can do are social distancing, which means avoiding crowds, public spaces, and non-essential travel; and self-isolating, which means staying home and away from anyone who doesn't live in your household as much as you possibly can. Some cities and states have now issued local restrictions for these strategies.

**Lewis:** *"Nothing is a substitute for social distancing. The virus can only spread person-to-person. This is a virus spreads via droplets. So either you are – and I know this is getting a little gross – but either you're exposed to someone else's respiratory droplets, or these droplets have landed on a surface and are sort of waiting there, if you will, until they can move to a human host. The social distancing – this business about staying six feet away from people, that's roughly the range of respiratory droplets when someone coughs or sneezes. Okay, so the six feet thing is not arbitrary. And then the whole business about washing our hands, you know, very conscientiously, and cleaning surfaces – this virus is actually extremely vulnerable to soap.*

*So the virus has a capsule around it made of lipids, and so they're kind of a tangle of fats, and those are disrupted by soap. So again, it doesn't have to be fancy, this is where washing your hands for 20 seconds is crucial."*

Please note that standard hand or bath soap is just as effective as antibacterial soap.

If online shopping and delivery options are available to you, please try to make use of them as much as possible. If you must travel out for supplies like groceries and medications, try to do so no more than once a week. If your store is offering this, visit during special hours for senior or at-risk customers. It's a good idea to reach out to your doctor and pharmacist to try to obtain an extended supply of your medications, to avoid having to visit the pharmacy as often.

While you are out, try not to touch things that many other people may have touched – examples are doorknobs, elevator buttons, handrails, and PIN pads – and if you must, try to do so with gloves, a handkerchief, a tissue, a disinfectant wipe, or your sleeve. In waiting room areas, avoid touching the chair backs, tabletops, or reading material.

As for facemasks, the Centers for Disease Control are advising everyone to wear cloth face coverings whenever they leave home, especially in situations where you might come in contact with other people. This is a supplemental measure and does not replace the need for social distancing. This recommendation is for cloth masks or coverings like a bandana or scarf, NOT

surgical masks or N-95 respirators. Those are in short supply in many places and should be reserved for health care professionals and caregivers. There are many instructions for making masks on YouTube and social media.

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If you have symptoms that feel like a cold or the flu, you should reach out to your care team immediately. Symptoms of COVID-19 can vary from person to person, but the most urgent symptoms are fever, difficulty breathing or shortness of breath, persistent pain or pressure in the chest, a tired, confused feeling, and a bluish tint in the lips or face.

If you, or someone in your household, is experiencing any of these symptoms, or any other symptoms associated with a cold or flu, such as a fever, congestion, or body aches, it's best that they also isolate within your household – sleeping in a separate room, limiting contact with other people in the house, and, if possible, using a separate bathroom. Their laundry should be washed separately, and often, and they should never share household items such as dishes, drinking glasses, cups, eating utensils, towels, and bedding.

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In all of this, one of the biggest challenges might be isolation itself, particularly if you live alone. Feelings like fear, depression, anger, frustration, and resentment are perfectly normal. Try to find ways to use technology to keep in touch with family and friends – both on the phone and through web tools

like FaceTime, Skype, and Zoom, which can offer face-to-face contact with loved ones who are far away.

**Lewis:** *"I just encourage people to remember that although we are physically separate, we have these really neat ways to remain in contact. I don't think there's anything more heartening than talking to a friend, making sure they know you're thinking about them and vice-versa."*

Exercise at home, read, watch movies, listen to podcasts, do hobbies, and generally find ways to pass the time that you enjoy and find relaxing. We've included links for free online movies, books, and puzzles. There are also many online courses, get-togethers, and musical events that are now available and open to all.

The stress of self-isolating and social distancing could be a trigger for alcohol or drug use or abuse. If you rely on recovery services or a support group to treat a chemical dependency, plan ways to access care from home to prevent relapse. Both Alcoholics Anonymous and Narcotics Anonymous offer online resources including virtual meetings.

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This is a challenging time for anyone who needs medical care, and your NET treatment may become more difficult for a while. Know that you are not alone. All of us at the NET Research Foundation, and our colleagues at other organizations around the world, are working hard to make sure you are informed and

empowered to protect your health, even as this pandemic continues.

Be smart, be safe, be confident, and as always, be NET wise.

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Thank you for tuning into NET Wise. My name is Laran Hyder. I'm the Director of Education and Outreach for the Neuroendocrine Tumor Research Foundation and serve as Executive Producer and Co-writer for this series. It was produced and co-written by David Hoffman of CitizenRacecar. Please visit [netrf.org](https://netrf.org) to see all of our up to date COVID-19 and NETs information. Like us and follow the NET Research Foundation on social media. This episode was made possible by the generous support of The Vincent E. Taylor Patient Education Fund, Advanced Accelerator Applications, a Novartis Company, Lexicon Pharmaceuticals, and Ipsen. This is a production of the NET Research Foundation. We're committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer. We fund research to discover cures and more effective treatments and we provide information and educational resources. Please visit us at [netrf.org](https://netrf.org)

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