NETWise Episode 51 (Transcript)

A New Year— Where We're Going

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
As the new year begins and we turn the page on 2025, it would be easy to frame this moment as a celebration of how far the neuroendocrine cancer field has come, but this episode isn't about looking back. It's about standing at the edge of what's next and asking a more important question, where are we going? I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to NETWise, the podcast designed to inform, empower and guide patients and caregivers through the world of neuroendocrine cancer. To understand where the field of neuroendocrine cancer is headed, it helps to appreciate the scale of effort behind it, not just the discoveries, but the community of scientists, clinicians and patients, all moving forward together. Elyse Gellerman, CEO of NETRF, shares what it feels like to stand at this moment with momentum behind us and possibility ahead.

Elyse Gellerman, MHS, Chief Executive Officer at NETRF:
The biggest source of hope entering the New Year is the large group of scientists in the room at our 2025 Margie and Robert E Peters and Neuroendocrine Tumor Research Symposium. This is a dedicated group. It is amazing to see their interaction, their collaboration, their dedication to discoveries, to developing new treatments and really impacting the lives of neuroendocrine cancer patients for the better.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
That sense of momentum is grounded in real advances in patient care. One of the most significant shifts in recent years has been in targeted therapies that are actively extending and improving patients' lives. Dr. Martyn Caplin has seen these changes firsthand, advances once considered experimental, are now reshaping everyday care.

Martyn Caplin, MD, PhD, FRCP at University College London:
There's been massive advances which have extended patients' lives. And the biggest advance and the most exciting, I think, is still PRRT with the lutetium treatments currently so the beta emitted lutetium dotatate, or dotatoc. I think it has transformed care. And I think the next transformation is going to be the alpha emitters, which are coming through the actinium and the lead. And then there are other new isotopes as well.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
The future of this field doesn't stop with today's successes. It depends on what comes next, on the ideas researchers are willing to imagine and invest in before outcomes are certain. Dr. Carl Gay turns our attention to the next wave of neuroendocrine carcinoma research, where immune-based approaches and emerging therapies are starting to move from theory into trial.

Carl Gay, MD, PhD, MD Anderson Cancer Center, Houston, TX:
I think that he's done a great job at this, at this meeting, or kind of reflecting on those two decades now. I think in looking a little bit forward, one of the things that NETRF has contributed to that could really pay off in the in the near future, some of the cell therapies, like the CAR-therapy trials, now that's a that's a high risk, high reward proposition, but we've seen it pay off in other tumors. They funded the science for that, and now funding the trials for that, and that's something that could really change the landscape of how we… of how we treat these tumors. Because, as I mentioned before, if you can engage the immune system, you know, the benefit of all of these therapies that primarily just sort of set out to kill cancer cells that are dividing, there's always going to be some way for the cancer to escape that– it's a lot harder for cancer cells to escape the immune system. It's not impossible, but it's a lot

harder, and so I commend them for that sort of high risk, high reward. And it's going to be really exciting over the next couple of years to see that go from preclinical work funded by the foundation to now clinical work, and actually see how the patients experience that in the trial.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
What's changing isn't just the number of options, it's how researchers think about targeting this cancer, looking more closely at the surface of neuroendocrine cancer cells and how they interact with their environment, and using that insight to drive precision.

Carl Gay, MD, PhD, MD Anderson Cancer Center, Houston, TX:
There's been a huge conceptual shift in just how we go about treating these tumors, even in the few years that I've been collaborating with the Neuroendocrine Tumor Research Foundation. The sorts of drugs that we were proposing testing in our models four years ago or five years ago when we submitted our first grant here, I won't say are obsolete now, but there's been such a shift to some of these surface targeting strategies, and that really first paid off in the lower grade NETs, right with, you know, with some of these radio ligands. And I think now increasingly, we appreciate that, you know, these tumor cells are aberrant enough and have a unique enough cell surface that you can probably direct pretty much anything you want against tumors that way. And you have to be– not to not to underestimate any of us here– but you have to be a little less clever about how you approach it, in that way, it's a little bit more of a blunt instrument. It's still targeted, it's still personalized, but you can occasionally luck into things that work in something closer to a one size fits all fashion. And so now it's, it's rare to see a talk at this year's event that doesn't at least briefly touch upon something that's being expressed at the cell surface that might be amenable to, say, an antibody drug conjugate. These were not things that were being talked about even just a couple of years ago, here.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
As the field pushes toward new targets and more sophisticated science, some of the biggest barriers to moving the field forward remain surprisingly human. Dr Iacovas Michael brings the conversation back to the clinic where language, understanding, and real-world models can either advance progress or quietly slow it down.

Iacovos Michael PhD, Sunnybrook Research institute and University of Toronto:
It makes sense to me, to us, it doesn't make sense to our patients. When you're a patient, you go in the clinic and you say, I have cancer. Hey, but don't worry, you have the neuroendocrine tumor. So, it's a tumor, or is it a cancer? It's only it's not a carcinoma, it's a cancer, but it's a tumor we have every time to explain to them. Or we have neoplasm. We call them tumors, and we call them carcinoma foundations. This is the biggest gap, because we can talk all we want about omics and models and computational, if we don't have models, and we're still– as a scientist, we have work, because we need models. We have to prove this. How are we doing with models? These are the patients. This is what we have to really focus on right now. Let's help the patients who really need us, and then we can go back, and this time will be more of this.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Looking ahead, some of the most important advances aren't about refining what already works, but about finding new targets for neuroendocrine cancers that no longer respond to familiar strategies. Dr. Carl Gay looks towards the next chapter of care, where immune based therapies and surface targeting are opening new possibilities for neuroendocrine cancers, particularly those that have lost somatostatin receptor positivity.

Carl Gay, MD, PhD, MD Anderson Cancer Center, Houston, TX:
I think, in looking a little bit forward, one of the things that could really pay off in the in the near future, some of the cell therapies, like the CAR-therapy trials, and that's something that could really change

the landscape of how we treat these tumors. If you can engage the immune system, you know, the benefit of all of these therapies that primarily just sort of set out to kill cancer cells that are dividing, there's always going to be some way for the cancer to escape that it's a lot harder for cancer cells to escape the immune system. It's not impossible, but it's a lot harder. There's been a huge conceptual shift in just how we go about treating these tumors. There's been such a shift to some of these surface targeting strategies, and that really first paid off in the lower grade NETs, right with, you know, with some of these radio ligands. And I think now increasingly, we appreciate that, you know, these tumor cells are aberrant enough and have a unique enough cell surface that you can probably direct pretty much anything you want against tumors that way, but you have to be a little less clever about how you approach it in that way. It's a little bit more of a blunt instrument. It's still targeted, it's still personalized, but you can occasionally luck into things that work in a something closer to a one size fits all fashion and so now it's rare to see a talk at this year's event that doesn't at least briefly touch upon something that's being expressed at the cell surface that might be amenable to, say, an antibody drug conjugate. These were not things that were being talked about even just a couple of years ago.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
One of the clearest signs of a field's future is who shows up to build it, new researchers, new ideas, new energy. Elyse Gellerman shares what it means when young investigators choose neuroendocrine cancer as the focus of their work, and why that choice matters for what comes next.

Elyse Gellerman, MHS, Chief Executive Officer at NETRF:
I'm most proud of the growth of the scientific community and the people that we have recruited to be neuroendocrine cancer researchers at institutions all around the world. We have funded about 77 institutions, and we have had wonderful success. Many of the young career researchers, probably about 90% of them, are still in research today, and all but a few are in neuroendocrine cancer research. So we are building the scientific community, and at the same time, we have really developed our patient education resources to help those with neuroendocrine cancer and their families understand a very complex disease and have the resources and education that they need.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
For those researchers, the future isn't working independently: it's working in collaboration. Alpha health represents a new generation of scientists thinking across disciplines, looking for patterns, biological overlap, and connections that can improve research.

Elsa Hadj Bachir, PhD Research Fellow in Medicine Dana-Farber Cancer Institute:
We need to keep sharing everything we do. I mean, apart from being in the lab and doing lab meetings, and also with like some other researcher that work on lung cancer, lung cancer, skin cancer, all associated with neuroendocrine figures. And it really helped me to see that there is sometimes common pathway and some universalities between the different locations and all touched by the neuroendocrine tumors. And I would say that what I'm expecting from next year and what I really want to achieve is bridging everything we know from the different organs and keep sharing everything. And when I say everything I mean, models, cell lines, how we think about our project and really make a link between all the different organ locations and find maybe common phenotypes or things that can then apply as biomarkers, as therapy or whatever. We are not here yet, but I would say: yes, keep making bridges.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
As science advances, perspective becomes essential. Dr Pamela Kunz places these developments within the broader arc of cancer research, explaining why neuroendocrine cancer now demands the same attention as any other field in cancer.

Pamela L. Kunz, MD at Yale Cancer Center:
The treatment landscape has changed emerging treatments and science, opportunities and unanswered questions. Neuroendocrine neoplasms are really not that rare. They are deserving of high quality, basic, translational and clinical research efforts. We have made exponential advances in the

field. We have more to do, however, the future will require multi-institutional networks, us, all of us, working as teams, sharing of data, and I think importantly, close patient engagement. NETRF has catalyzed so much of this work in the field and has helped build and sponsor the next generation of net scientists. I know these advances provide me with hope, and I know that they provide hope to our patients.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
But science alone doesn't determine outcomes. Access to information and education do too. Anna Greene, Chief Scientific Officer at NETRF, speaks to the role of knowledge, not just for researchers, but for patients, and to why understanding the disease can change the course of care itself.

Anna Greene PhD, Chief Officer of Research at NETRF:
Education, for us, is part of care for neuroendocrine cancer. So we think that when patients and clinicians know what to look for, they're more likely to get to the right tests and the right specialist sooner. So we have different educational tools in our toolbox. We have a NETWise podcast. We have a new patient guide that will be issued soon, but our general patient guide is phenomenal. It's a great way to get an introduction to what you need to know about the disease for patients, but also for caregivers. We also have patient conferences and we post videos of those after the fact on our YouTube channel. So there's also a wealth of resources in our YouTube channel as well. Our goal is really to help patients walk into the clinic informed and be prepared to participate in discussions with their medical team. We want them to feel comfortable advocating for themselves, because that's so critical in getting the best care. We think that this will reduce fear, it will improve communication, and this will ultimately support better outcomes for patients.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
As treatments improve and survival extends, the conversation naturally evolves beyond just managing disease to living and even thriving with it. Elyse introduces this idea of thrivership, a way of reframing life with neuroendocrine cancer that acknowledges complexity, resilience, but also possibility.

Elyse Gellerman, MHS, Chief Executive Officer at NETRF:
Thrivership is the integration of how someone can live well and not only survive but thrive with neuroendocrine cancer. It’s a philosophy that we have brought into our patient education program over the last several years, under the leadership of Jessica Thomas, our Director of Patient Education. And we know that health is the physical plus the emotional, and it really is an acknowledgement of the strategies, the tips that someone can employ to really live their best life with neuroendocrine cancer. For many patients with slow growing tumors, this is a marathon, not a sprint, and it is important to to really consider the other aspects of someone's life, because they're not defined by their cancer, it's something that they have and that they manage with their care team and to the best of their ability, but they also have the opportunity to live a full and rewarding life.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
This idea becomes real in the voices of patients. Nancy Lewis shares what thrivership means in her own life, not as a theory, but as a daily practice shaped by perspective, gratitude and choice.

Nancy Lewis, Patient and Advocate Living with Neuroendocrine Cancer:
I like the word “thrivership” because a lot of people say, oh, you're– a you're a cancer survivor and just surviving this thing. You know, I'm thriving with it. I’m… I’m… I am thriving with it. And I know that not every day is going to be my best physical day. I know that, but I get a choice to think about it the way I want to think about it, and— and I'm thriving with it.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Hope doesn't always arrive instantly. Sometimes it's steady, sometimes it's learned. Nancy reflects on how hope evolves, especially in a disease where progress and research is real and ongoing.

Nancy Lewis, Patient and Advocate Living with Neuroendocrine Cancer:
You hear the “cancer” word, and a lot of people, your mind just goes straight to, well, okay, that's it, but there, there is hope, there is work being done all the time, and you just don't know. You don't know what tomorrow's gonna bring, and you don't know what next year is going to bring. And I believe that they were going to find a cure. I believe that. And so I would tell people, hope is one of the most important things, and just keeping a positive mindset, not not thinking about not letting cancer define your life, thinking about the things that make you happy, and thinking about the things that you're grateful for, and keeping that in in your mind is just as important as all of the medical work you'll do.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
For many patients, thriving also means learning how to speak up; how to ask better questions; how to push for answers. Jake Dawson talks about self-advocacy, not as confrontation, but as participation in your own care.

Jake Dawson, Patient and Advocate Living with Neuroendocrine Cancer:
Advice for cancer patients or anybody, as far as, like, advocacy goes is: be annoying. You know, sit on the phone for an hour and see what you can get done. Well, I think what's tough is like you learn to be you learn to become an advocate.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
From the clinical side, that engagement isn't just welcomed, it's necessary. Dr Caplin explains why informed, persistent patients are essential partners in good medicine.

Martyn Caplin, MD, PhD, FRCP at University College London:
It's important to be able to be self-advocate. One wants what's best for the patient and the patient there. It's– it's their life, it's their condition. They have to be. You know, if you have a question, quite right, you have to ask it, and no matter how silly it may seem. And also, if you, if you don't think you're getting the most experienced person or the right treatment, then speak up about it.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Behind the science and the stories is stewardship. Todd Gilman reflects on the responsibility of supporting both research and patients and why education, funding, and trust can't be separated.

Todd Gilman, President of the Board of Directors at NETRF
Our number one drive is to support the patients and impact the patients with outcomes from our research, that's a holy grail. More presently, we found that another important way to support the patient community is through information and education, because it's very common, and it was my experience that one minute you have no idea that even neuroendocrine cancers exist, and the next minute, you're told by a medical professional that you have some form, some type, some stage, of neuroendocrine cancer, and you need to turn somewhere, like, where am I going to get information? What is this?

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
The direction is coming into focus. Anna Greene outlines the work already in motion. The roadmap to research a framework built around early detection, better treatments and precision medicine.

Anna Greene PhD, Chief Officer of Research at NETRF:
We created our research roadmap around three pillars that are tightly connected and aligned with the most urgent patient needs. And those three pillars are early detection. And so this should address the diagnostic delay that we're familiar with. We really want to ultimately stop the pattern of late metastatic

diagnosis. The next pillar is improved treatments, and this should address the reality that some patients still run out of options. We need to give every patient at every stage of their journey better options, especially those currently underserved by existing therapies. And the third pillar is precision medicine. We want to make sure that each patient gets the right option at the right time, and we want this to be guided by biomarkers and their tumor biology. And so the reason we created the roadmap is because the science is ready. We have the tools, we have imaging, we have sequencing, we have liquid biopsies, we have radio pharmaceuticals, and we can really make major leaps if we start investing strategically. And so we believe that we have a responsibility to organize and accelerate this work. And so that's why we created the research roadmap.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Momentum creates responsibility. Elyse speaks to the urgency of this moment. Why awareness, earlier diagnosis and continued investment matter now more than ever.

Elyse Gellerman, MHS, Chief Executive Officer at NETRF:
Awareness is key, and neuroendocrine cancer is many times misdiagnosed. It's estimated that some patients go three to five years before they get an accurate diagnosis. So I think the important thing for patients is: listen to your body. If you have a sense that something is not right, press for the appropriate testing. Let your physicians know that something is not right– and, and ask that physician if your symptoms do kind of line up with some of the symptoms we talk about on our website, to consider neuroendocrine cancer. And I think, just for– for the general public, be aware of neuroendocrine cancer. This is a disease that took the lives of Steve Jobs, Aretha Franklin, Jimmy Buffett. So you know, there are many people, some celebrities, who have it, some people who are taken from us too soon. It is uncommon, but it is increasing. So it's important that everyone is aware of this, and I would encourage everyone to learn more about the disease, to check out what NETRF is doing to support us, if they can, at NETRF.org, it is so important that that we accelerate the progress and that we double down on our mission.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Progress is never solitary. Dr. Po Hein Ear reminds us that discovery lives in collaboration, in teams that share challenges and build their work and ideas together.

Po-Hien Ear, PhD at the University of Iowa:
And it really takes a team. As you can see, it's different people from different training backgrounds. So but I think together, we– we are unstoppable, and we're, we're, we're coming up with new discoveries and new findings. I just want to let everyone know that we're working hard on all aspects, so we are looking for therapies to improve the symptoms, management. We're looking for therapies to stop the cancer or to eliminate the cancer.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Big shifts are almost never singular moments. They're assembled over time and with a lot of support, NETRF board member Josh Mailman, talks about how each contribution, each study, each grant, each supporter, becomes part of something much larger.

Josh Mailman, Patient Advocate and Board of Directors at NETRF
Our new tagline is "finding a cure". But I want people to recognize we find cures by building blocks, and that it's hard to measure your singular donation into how important that building block is, but you're raising the level of research in this underserved community, and you're keeping people focused on it. That is amazing. I mean, we've given nearly $40 million in research. We've had some wins, had some– some ability to move the needle forward.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Across every voice, every researcher, every supporter, one thing holds steady: commitments. Not to any one moment or a milestone, but to the work that continues.

Elyse Gellerman, MHS, Chief Executive Officer at NETRF:
It's an exciting time to watch what's happening in neuroendocrine cancer research. The scientists who have joined us at this symposium are making strides every day, and I think there's hope for patients, and what I like to tell my patient groups when I talk with them is, you may not see them, but there is a small army of researchers in laboratories around the world working on your behalf. They are working to make your lives longer and better. And I think that's the best sort of hope to see the energy that we've seen at this symposium, to see the dedication of these researchers and know that they are committed to the search for new treatments and cures.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
The future of neuroendocrine cancer treatment is being shaped by scientific collaboration and by talented and dedicated people committed to advancing the field. This isn't just a promise: it's momentum. It's a direction. And, this is where we're going.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
Thank you for listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to NETWise, the podcast designed to inform, empower and guide patients and caregivers through the world of neuroendocrine cancer.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
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Jessica Thomas, LCSW, Director of Patient Education at NETRF:
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