

Transcript: How a \$64 Million NIH Grant Will Transform Palliative Care Across Lifespan | Part Two

Welcome And The NIH Grant

Jeff Haffner 0:00

Welcome to TCN Talks, and Anatomy of Leadership. Today we continue our conversation with Dr. Jean Kutner. How a \$64 million NIH grant will Transform Palliative Care Across Lifespan. And now, here's Chris Comeaux.

Chris Comeaux 0:22

So, as we go into this next segment, really want you to do some prognostication as we look into the future. So, fast forward, let's say five years, what concrete changes would tell you that Ascent is succeeding, realizing some of your vision and your dream for this?

Dr. Jean Kutner 0:40

Actually, we just got approval of our evaluation plan this morning, so I know I know exactly what we're going to be measuring. So I think with in five years, I think there's there's some sort of process measures and some outcome measures I would think about. Some very concrete, sort of easy to measure things is that we do have an increased number of palliative care investigators from institutions that maybe have not had a strength of palliative care research. That's one of our foci is to bring sort of more people and more from organizations that maybe don't have a real strength of palliative care research, bring those into the fold. Um, as well as disciplines. Uh, you know, if we can bring in and identify and support more investigators from disciplines that are maybe less well represented on the research side of things, Chaplain C and social work being a couple of those key ones. Measuring new collaborations, back to your first question, to me. We see our role overall as connecting. There's new research collaborations that come out of this. Within five years, we would hopefully start to see some of our early awardees. So we will be awarding our first round of pilot grant awards and research scholar awards in May of this year. So in five years, those early awardees are hopefully turning that early ascent investment in their work now into larger extramurally funded awards like from foundations or from the NIH. We would hopefully have an expanded pool of mentors, so people that can support our more junior investigators. I think I mentioned earlier that right now there are six NIH institutes that are supporting Assent. We would uh hope that more institutes uh get on board within five years. And that back to this question of how do we get information out into practice if we have evidence that some of our partner organizations, like healthcare delivery organizations or professional societies or advocacy

organizations, are using data that was generated by or supported by Ascent to actually change practice and policy. And then I guess maybe sort of the not directly patient focused, but the uh hope, and I guess I would say that hopefully evidence of that success is that there is another five-year ward from the NIH to support these activities beyond this initial five years.

Chris Comeaux 3:07

Which maybe gets to my next question. Fast forward 10 years, if a SIT fully realizes its potential, what might be different about how patients with serious illness experience care in our country?

Dr. Jean Kutner 3:18

Yeah, I think this goes back to that um what our our overall vision, the and these are the true outcomes that are important, would be that there really is enhanced access to high-quality evidence-based care, and that that's occurring across the lifespan and across care settings care settings, that we have ways where care is directly informing research and that research is directly informing care. If we could get to the point where there's no longer these gaps in the care continuum for people with serious illness and those who care for them, I think in those of us that that are you know deliver care, either as clinicians or as organizations, well recognize that there are, you know, there's pockets, hospice, there's inpatient palliative care, there's some palliative care clinics, and then there's these big gaps in between. So if we have the evidence to show what is most effective, and then that changes policy and payment, and then we could have that nice care continuum. I would love it. I mean, 10 years is probably too short of a window for this, but I think we have to keep pushing toward it, is that in 10 years our research questions and the things that we're studying are actually refining care rather than addressing what are really still basic gaps in care that exist today. And then I think also for palliative care research to be seen as an actual viable career pathway for all palliative care relevant disciplines. I you know, we often talk to people who say, well, I'd like to do palliative care research, or I have these research questions, and I'm not sure how I create a career out of that. So if that is really seen as a viable career, that will be what keeps the palliative care research uh going into the future.

Chris Comeaux 5:07

So would you envision that maybe palliative care is provided much more seamlessly and further upstream? Is that kind of an interpretation in in your tenure vision? And is that why that lifespan approach in this grant is so important?

Dr. Jean Kutner 5:22

I think it's two things actually, Chris. I think it's both the true care continuum. So, you know, from more upstream through all the way through the trajectory of illness, and then true like person lifespan. So from like neonatal up through old age. And then there's that group that kind of lives in the middle there, the either the those are the adolescent young adults or the younger adults or the people that have a serious illness and they kind of graduate out of the pediatric world, but they still have a serious illness, and they end up in our adult world, which is not really designed well for people that have had pediatric or adolescent type illnesses. So I think it's both. I think it's the care continuum as well as the the true lived lifespan.

Chris Comeaux 6:12

And would you envision that people would experience powder care perhaps earlier in their serious illness trajectory as part of this, or not necessarily?

Dr. Jean Kutner 6:23

I think so I here, I'll put my read. I think as the evidence shows that it's beneficial. So I think that's part of the that's part of the question is delivery of what to whom when. And I think we have some pockets of understanding that, but certainly across all disease types and across the the age span, we have much more to learn about delivery of what, you know, sort of what dose of what to whom when in that trajectory actually makes a difference.

Chris Comeaux 6:51

I was actually doing prep this morning uh for a future podcast. Um and we're actually gonna have Kathleen Bitten and Terry Yarbrow, who just published the book about VR as a care modality in the serious illness population, so virtual reality. Um and so I don't know if you bumped into that, and um, but we're actually gonna have a podcast coming out, I think in it is probably about four weeks after yours. And I went out kind of like, what? VR is an actual modality. So will you guys be looking at some alternative therapeutic modalities as part of this grant potentially?

Dr. Jean Kutner 7:24

So it would certainly, so remember, half of you know, at least half the money's going out the door to investigators who bring research ideas to us in the form of pilot grant awards or research scholar awards. So VR as a modality to address symptoms, quality of life, et cetera, the things that we care about in palliative care would certainly be consistent with the ascent mission and and interests. I d I actually don't know if we got any for polls in our first round that have anything to do with VR, but um, I've seen it work here. Our music

therapists actually here at University of Colorado Hospital have uh done some nice work with VR. So I think it's viable. And that's what see, we need evidence.

How To Partner With Ascent

Chris Comeaux 8:06

Yep, absolutely, exactly. So for leaders, clinicians, researchers, or maybe even healthcare systems that are listening to our podcast, how can they engage with, partner with you in this work? And what kind of collaborators are you hoping to attract?

Dr. Jean Kutner 8:21

So I would say Ascent is interested in partnering with investigators, with healthcare delivery organizations, with policymakers, with clinicians, really anyone who's passionate about care for people with serious illness at those who care for them. Because in order to be relevant, I remember this is you know, we we see ourselves as stewards of this resource, and we want to make sure that it's relevant to the field. So in order to be relevant, ensure that these resources have the biggest impact and fulfill that congressional mandate to actually make a difference. Um, Ascent really needs engagement and connections with a wide range of uh people and organizations. The best way to connect with us is through our website, uh, which is Ascent Palliative Care, all is one word uh. And then on the Ascent website, there's an opportunity to sign up for our mailing list. And as part of that, we ask, like, what are your interests? What would you be interested in, interested in either learning about or or um getting or participating in? We also have a LinkedIn site that the Ascent Consortium LinkedIn, to get updates and announcements of what's going on. So we we actually really do need to hear. We need to hear, like I said, from investigators about you know what would be helpful to them to be able to move their research forward. We need to hear from clinicians and care delivery and people living with serious illness to say, where do they see that need for evidence? And same with policymakers. What is the evidence that they need to be able to make their arguments for changing policy?

Leadership Lessons For A Big Consortium

Chris Comeaux 9:58

We're gonna make sure in the show notes that we're gonna include both of those links to make it pretty easy for people to be able to get access to that. So, Gene, you know, leadership is also my passion. So definitely want to put in a question here. So, what does leading something of this magnitude require? Like, I mean, it's kind of mind-boggling

when you describe, I mean, just to pull this grant off was huge. So, from a culture standpoint, a governance standpoint, collaboration, maybe frame your answer like pre and then post. And I'm looking for those leadership lessons.

Dr. Jean Kutner 10:32

Yeah, that there's um this is definitely bringing to bear all of my prior leadership experiences because it is, it is large, dispersed. Um, because even if you look at where our five principal investigators are, we're at five different academic institutions, and then our key personnel are across, I think a total right now of 26 um institutions. So creating the culture, the structure, and all of that. And uh, I would say we um put a lot of time and effort up front into creating how we work together. Uh, and like I said, we we as the Ascent principal investigators really see ourselves as the stewards of a precious resource. And we're all been very clear that we are mission-driven. We are all in this for the mission, and that's where we start. That's where we started in. We are doing this because people living with serious illness and those who care for us are depending on us to develop that evidence to make sure that they have the best care possible. That's really our North Star. And that's I think I think that's really important because you can get so caught up in sort of the the details and the the day-to-day and all that, but to come back to that of, you know, you know, not to be cliché, but start with the why. I feel very fortunate and it was very purposeful to have an outstanding and dedicated both leadership team and administrative operations team. We have purposefully uh selected people for the team who share that vision and mission. And then, like any complex organization, that's where we start. And we've also early on, even as when we were first writing the grant proposal, I still have the document where we wrote out our guiding principles, guiding principles for how we act, how we interact with each other, um, how we how we make decisions, how we communicate, and being really explicit up front about how we function together. And I think that's been really fundamental for making this go forward from writing the grant proposal to startup and now implementing. And we also try to have fun, you know. Uh people ask, you know, how's it going? I said, oh my gosh, it's so it's so fun. I so enjoy working with this group because everybody is so committed uh to the work. I also honestly think that it it's helpful to have a whole leadership group of people that are palliative care professionals, because in some ways you sort of have a shared language and uh sort of applying, I'm a firm believer in applying palliative care principles to leadership, like seek first to understand, identify shared goals, really listen. Those sort of, those sort of palliative care principles that we're so used to from a clinical sense, applying those to actually making this work.

Chris Comeaux 13:28

And it sounds like you still see patients do a lot of your team as well as part of their roles, or is it kind of a mixed bag?

Dr. Jean Kutner 13:35

I would say everybody who has a clinical background is as far as I know, is still seeing patients. I mean, some some folks don't have a clinical background. I don't our statistician, I'm pretty sure, is not interested in seeing patients. But yeah, there yeah, the the rest of us are, as far as I know, are are all seeing patients. Yeah, in fact, we often have to schedule around rounding. Oh, I'm rounding that day on patients. I'll be, you know.

Policy Evidence And Payment Models

Chris Comeaux 14:01

Do you think this might influence whether there may be a reimbursement for pre-hospice that powder care is or is it more might be incidental to the work that you're doing?

Dr. Jean Kutner 14:13

So I think that would be uh fair game for evidence generation. In fact, I was just at the uh AHPM, HBNA Annual Assembly and State of the Science meeting last week and had a lot of discussions with people about this interface between research and policy/slash um payment mechanisms. And my question to the people who live in the policy space is what evidence do you need us as researchers to generate to be to for the people that are active in that policy payment model space to be continue to move forward that argument toward having a payment model for that evidence-based care? So I say that is totally fair game in terms of a research topic.

Final Thanks And Closing Quote

Chris Comeaux 15:01

That's incredible. Final thoughts, Jean. This is your opportunity. I mean, you have an incredible audience of hospice empowered care leaders. So from you to them, what are your final thoughts?

Dr. Jean Kutner 15:12

First, I would say thank you. Thank you for what you are doing on a daily basis to care for people with with serious illness. And also remember that you are the experts in what are important research questions that then we can work with our researchers to answer. So I

really encourage that connection between our clinicians and our care delivery organizations and our policymakers and the researchers. So thank you for what you're doing and your expertise is so important as we move forward the field. I do think it's an exciting time, Chris. It's an exciting time for palliative care. It's an exciting time for palliative care research. And I mean, I know I'm the eternal optimist, and I just think that we are headed in such a great direction. I think the, and I really felt this last week at Annual Assembly in State of the Science, is that that just the energy and the enthusiasm and the quality of the science is in a better place than it ever has been, which makes me really optimistic about the future. And there are many investigators out there now, you know, doing palliative care research, really moving forward the field in innovative ways. And Ascent is just a resource to help move forward, uh, help move forward the field. So we've really let us know how, you know, this is your resource. This is tax there, taxpayers' dollars, right? Let us know how Ascent can help you.

Chris Comeaux 16:42

I want to thank you, Jean. I mean, you and your team, but also you. Like everybody I bump into is like part of the Jean Kutner fan club. Your reputation precedes you, and you're just such a humble, brilliant person. I mean, you really do embody the ethos of our field, and I'm just blessed to have had you and my past, and I'm so glad we're able to reconnect. And congratulations. This is an amazing milestone. I realize that the hard work is ahead of you, but just to get the opportunity is so cool. And like you, um, you know, I'm super enthusiastic about the future, but also the timing of this kind of feels weighty. You know, the baby boomer is going to be the largest demographic we've ever cared for, and we're just on the front part of that. And the fact that, you know, I asked you the question about 10 years. I mean, the next 10 years are where I think the ascent actually of the slope of the line of the volume of baby boomers are aging out, serious illness, is between now and the next 10 years, even a little bit into the early 2040s, the slope continues, but it's not quite to that same level. And I think I don't know if it's 2060 or 2050, whatever it is, when the when the full silver tsunami kind of washes up on the shore. So the timing of this available um for us to up the care for baby boomers as well just feels profound. So I'm so excited, so happy for you guys, and we'll have you back over the time so we could talk about what's coming out of it. Yeah, absolutely. So thank you. Thank you, Chris. Appreciate you. Well, to our listeners, end of each episode, we share a quote, a visual. The idea is to create a brain bookmark, a thought prodger about our podcast subject to further your learning and growth and thereby your leadership. We're hoping it to stick like a brain tattoo. Be sure to subscribe to our channel. We don't want you to miss an episode. Be sure to check out the book, *The Anatomy of Leadership*, on Amazon. Tell your friends and co-workers about it. You know, it's easy for us to rail against the world and be frustrated by things. Let's be the change we wish to see in the

world. So thanks for listening to today's podcast, and here's our brain bookmark to close today's show.

Jeff Haffner 18:38

"Research shouldn't just sit on a shelf somewhere. It should be influencing care." by Dr. Jean Kuter. Thank you, USI, for sponsoring this podcast.