

The Dialysis Life: *Getting to the COR of IT*

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Hello, and thank you for joining us today.

My name is Justin Carr, and I am the patient services manager for Health Services Advisory Group End Stage Renal Disease, or ESRD, Network 15.

I'd like to welcome you back to The Dialysis Life podcast series. These podcasts are developed by the Network in conjunction with fellow patients in the Network's Patient Advisory Council, also known as the PAC (PAC).

The podcasts cover a wide range of ESRD-related topics and feature commentary and discussion with patients, Medicare representatives, doctors, and others touched by kidney disease. It is our hope that this podcast series will speak directly to the experiences of individuals with ESRD and their caregivers. The goal is to improve understanding of this complicated disease, and with that understanding, improve the quality of life for those touched by it.

Justin

Today we're *Getting to the COR of It*. We'll discuss the Centers for Medicare & Medicaid Services (often shortened to CMS), how it influences the world of dialysis, and its focus on patient and family engagement: what is patient and family engagement; why does it matter; and what can it do for you.

Joining me today to discuss these topics is Johannes Hutaaruk, the CMS Contracting Officer's Representative, COR or COR, for ESRD Networks 15 and 17. As a COR, Mr. Hutaaruk, or as he prefers to be called, Johan, is the liaison between Networks 15, 17, and CMS, a division of the federal government.

Let's talk more about the importance of CMS and the COR's role with Johan right now.

So welcome, Johan, and thank you so much for being here today. Um, could you please tell us a little bit about yourself and how you got involved with ESRD.

Johan

Um, yes thanks, Justin. Um, yeah. It wasn't like I came in kicking and screaming, but I originally came from Indian Health Service as an ICU nurse. I

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applied to CMS to work on process improvement. Even then, and coming on to CMS, I didn't really fathom, you know, all the intricacies I was really getting into. My thoughts were always trying to assist clinicians in addressing patient needs, but I had some workings with dialysis as a nurse. I know a lot of the large dialysis organizations, they would have vendors come in and dialyze a lot of our ICU patients. So, like when I—my involvement with the dialysis contract came about because basically we were short on CORs at that time, um, that were focused on ESD [End Stage Disease—short for renal failure disease] contracts, and so I came in there just trying to learn a lot of things. And so, that was my introduction to the ESD contract and involvement in CMS.

Justin

And we're very glad to have you as an integral part of the ESRD community. You've been such a great advocate and such a great resource for us, so thank you. Um, so would you mind please telling us a little bit about kind of what CMS does regarding ESRD specifically, and its oversight of dialysis clinics, and then maybe, what your role as a CMS COR entails?

Johan

So, to address the needs of ESD patients, there is—just from the Social Security Act—and in caring for ESD patients, it's already not just in a contract, but in law basically; and so when we're using our [CMS'] funds, we definitely do monitor how it's [any care provider] taking care of patients, and if it's effective. And as a COR, I represent the contract officer with not just monitoring, but managing government contracts, specifically in this case, an ESRD contract. And also, as things, um, evolve and develop, that we incorporate some of those best practices in the clinical setting, as well. And so, as contractors, you guys go out and preach, as I say, preach the gospel of the best practices, and then we look at the numbers and see how things um, develop and um, and uh, improve, as well.

Justin

So that's very helpful information Johan, thank you. I think the importance of the government's role in ensuring ESRD patients get the best care possible is maybe not always evident to people, so speaking with you, I think, gives the federal government and CMS kind of a face, or in this situation, at least a voice, that we can put with the government's efforts. It kind of gives people something to attach all that to, so thank you.

I'd like to talk a little bit now about patient and family engagement, sometimes called PFE. So, I'd like to start by asking, what does patient and family engagement mean to you, Johan?

Johan

And so, with patient and family engagement, initially in my mind involves [giving] patients in their care activity, a say in how they're cared for, a responsibility for their care. It's about relationships and being engaged in all facets of—of life, and I think that's part of it. Um, just looking [at] engaging patients so that we can know a little more about them. Patient/family engagement is, um, that partnership together; the patients and the staff with the

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patient [at] the center, focusing on their needs. And who better to ask than the—the expert themselves, the patient.

Justin

Yeah, yeah, exactly! I totally agree. So, this leads me to ask you, Johan, as someone who sees a much larger picture of the dialysis world than the average person, why does it matter that patients be engaged in their care?

Johan

Um, to be engaged is to—to have—to have better health care. You're giving the clinician as much information as you can [by] being engaged. And you know, we have the surveys, the papers, things to fill out, and forms. Um, I think just sometimes you learn more, your questions will know more about you when you actually engage face-to-face. You [can] read stuff off a paper, but when I'm engaged with my provider or one of the clinicians I'm dealing with, speaking personally, they might need to get to know me better. They know how to better customize um, my care and, in a sense, I'm hoping that it'll help them treat me holistically. I don't want to be like, a lot of ESRD patients say, I don't [want] to be defined by my ESRD state, my kidney disease this or that, but I want to be defined by, you know, the totality of who I am. And so, I—I think by being engaged, the importance for a patient is, it helps in customiz[ing] their care, and it helps with treating a patient holistically. And I think the more you know about people, the more I think it helps with relationships, and with understanding

Justin

Yeah, you know, I think that's so true. Um, and I've seen, honestly, data, both anecdotal and you know, more, um, empirical data, that kind of supports exactly what you're saying, and how these engaged patients tend to be happier or have better care. I definitely see that. I wonder Johan, do you have any, maybe, stories or examples of how a patient and/or family took a role in shaping their experience, even if it's outside of ESRD?

Johan

Maybe from my ICU setting. Um, gosh, I mean, I remember just starting out in nursing and I mean, understanding how important it is to really involve patients in assessments. So, I get this patient, and I guess this lady has some right-lower extremity surgery either post op [post operation], and they come in to get a report and, you know, [to see if] everything is going okay. I see them the next day again, I have the same patient—yeah continuity of care—anyway, this lady still has some swelling in her lower leg, lower extremity. You kind of reassess the patient. I knew to check her pulse—it's kind of weaker compared to the other side. Then I asked the patient, “How's your leg?” “Yeah, it's still in pain.” Things like that. She seemed to be requiring more pain meds, and she just said, “You know, it just hurts a little more for some reason post-op.” I mean, you know, I thought, “Okay, let me let the doctor know.” Because the surgeon, at times, you know, can be intimidating. So, I just called [the] surgeon up and just let him know, “[The] patient, you know, [has] weaker pulses.” I tried to sound more organized and to say, “The pain just seems to be greater, and the swelling's increased, and even the patient said they noticed some swelling.” So [the

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surgeon replies] “It’s okay, I’ll be by to assess, and thanks for bugging me.” So okay, he comes by, he assesses the patient and it goes “Oh, no, no. Well we definitely have to take the patient to surgery today.” [They] take the patient to surgery within like the next hour and a half. Again, just asking the patient. She kept asking stuff and saying, “It’s really bugging me and does not [feel] normal.” That’s a post-op. But you know, I listened to her and it really helped me as a nurse to say, “Whoa, wait a second.” That is so much better when the patient can actually talk. That was an important point, to understand it.

Justin

Thank you so much for sharing that Johan. You know it’s so powerful to hear how patients can benefit from actively engaging in their own care. I’d like to point out that if anyone listening is struggling with how to find ways to engage in their care, they can reach out to their clinic care team or to the Network with any questions or concerns.

Well, Johan, it has been a pleasure to speak with you today. We’re grateful for your time and dedication to improving the quality and experience of care for all those touched by ESRD. Thank you so, so much.

Johan

Thank you, Justin. It’s a partnership, definitely, and how can we help each other achieve sustainable goals. That’s like the generalized thought. But how can we—to put it into simpler terms—how can we help each other? That’s what we all should be about. And thanks for the opportunity to try to be of help.

Justin

Thank you, sir! I know we’ll make things better by working together—us and the patients, right? So, thank you and I look forward to speaking with you again soon, okay?

Johan

Definitely. Always a pleasure, Justin.

Justin

We hope you found this discussion of *Getting to the COR of It* helpful. Please keep a look out for the next episode in *The Dialysis Life* podcast series.

Thank you for listening. This is Justin Carr for Network 15. Take care. [Music]

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