

Network 15 *This Dialysis Life Podcast*, Episode III:

Learning More About the Learning and Action Networks (LANs)

Moderator

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Hello and thank you for joining us today. My name is Justin Carr and I'm the patient services manager for Health Services Advisory Group End Stage Renal Disease (ESRD) Networks.

I'd like to welcome you to the Dialysis Life podcast. These podcasts are developed by the Network in conjunction with patients on the network's Patient Advisory Council, also known as the PAC. The podcasts cover a wide range of ESRD related topics and feature commentary from, 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 learning more about the Learning and Action Networks. Learning and Action Networks or L-A-Ns, pronounced LANs, are patient and caregiver work groups that meet via phone and WebEx meetings to work on producing materials that help improve the lives of folks touched by ESRD. LANs differ by topic. For example, there are different LANs for reducing bloodstream infections, increasing the number of patients on transplant wait lists, and increasing the number of patients dialyzing at home. Authorized by the Centers for Medicare and Medicaid Services or CMS and overseen by the ESRD National Coordinating Center (also known as the NCC), LAN materials are created and vetted by the ESRD patients and caregivers from around the country. These individuals meet every other month for about one and a half hours at a

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time. Today we'll be meeting some patients from the network area who have served on a LAN during this past year. They're going to share their thoughts about their LANs, some of the work their LANs have been doing, and how the LANs can benefit all patients. The first person joining me today is Mr. Roy Widman, a member of the Network's PAC and also a volunteer with the Home Therapies LAN.

Roy welcome and thank you so much for being here today would you mind first please telling us a little bit about yourself and your experiences with ESRD

Roy Okay. I joined the home dialysis group because that's what I do is home dialysis. And I basically I think it's the thing that I had the most interest in any way. I travel around the country a lot between Wyoming, Colorado, New Mexico, Arizona and to me home dialysis is the only way to go.

Justin Yeah, that's great! I'm so glad that home [dialysis] lets you travel around like that, and that's one of the reasons we try to educate folks about it, because it really helps you be independent. And it sounds like it's a great fit for you! And [you] being on the Home LAN, thank you! We're very glad to have you as a part of our community. Could you tell us a little bit about the Home LAN and kind of what you've been doing this past year?

Roy One of the things that we've worked on and that came together was that we felt that we needed to get information [about home therapies] to dialysis patients earlier in their journey. My feeling was, along with them, that we needed to get information out to the doctors nurses and social workers earlier.

Justin Thank you. Do you mind telling me kind of just in general what you think the purpose of the Home LAN is?

Roy Well basically just that of creating information too, and getting stuff out to, people so that they can enjoy life more. Our product that we built was a series of flashcards or conversation cards. And these cards were set up of five or six different modalities or things, telling people what they could do under home dialysis, like traveling and family and different things like that. And I think it came up very well.

Justin Oh wow! Yeah that sounds very exciting! How do you think these tools will be used in the ESRD community? How do you see them going into play?

Roy These cards are conversation starters. You can go up to an individual, actually, I just talked to one on Monday I believe it was, and it was very easy to use the cards and say "do miss traveling?" or "do you miss being able to go see a new grandbaby?" or "go to a wedding?" or "go on a real vacation?" and it gets them started.

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Justin Well how do you see this being sent to other patients? How do you think it will get to their hands?

Roy I have primarily seen it through early visits to doctors or through the staff that the doctor has, like their social workers or nurses or something like.

Justin It's really cool yeah? It sounds like you really are making a really big impact with the work you're doing there! Tell me Roy what's been your favorite part of working on the LAN?

Roy Well there was quite a few things. I think one was just listening to the input of people from all over the country, actually and listening to their experiences and the things that worked for them and the things that didn't actually work for them. I think we were a lot of the same voice in what we were doing.

Justin It really is incredible to me Roy. I appreciate you talking with me about the work you've done. It really does hit home when I think about all the ways you and your fellow patients on the LANs can represent other patients and help raise up all the other folks who are living with ESRD. That's really powerful work so, thank you for sharing that, and thank you for what you've done, and thank you for being here. Do you have any other final thoughts on the LAN?

Roy I think one thing that comes to me, a long time ago I read a book, and I've forgotten what the name of the book [was] or who wrote it or anything like that, except there was one line in the book that really came to me. And this particular line, the main character stated that she didn't want an easy life, she wanted a meaningful life and I think doing something on the LAN, I felt that I was actually doing something meaningful.

Justin Wow! Yeah that's really powerful! Well thank you, your testimony really means a lot and I think it'll mean a lot for others to hear it. I know I've said it a bunch in this short conversation but thank you thank you thank you- that's really amazing! I really appreciate it Roy.

Justin I'd like to welcome with us now Jacque Harris, who's a member of our PAC and also member of the Kidney Community Emergency Response Learning Action Network or KCER [LAN] and Jacque, thank you so much for speaking with us today. I wonder could you please tell us a little bit about yourself and how ESRD has impacted you?

Jacque Sure yeah. I have been on dialysis for a little over four years. I was a typical diabetic patient and that what's caused my kidney function to go down and the loss of the kidneys, after about 32 years. And my doctor was very thorough. Every month I did my blood work when I went in and they kept telling me "your kidney function [is] going down real slow but it's going down" and I was like "okay?" I didn't have a clue and I think most patients do not understand what it means to have End Stage Renal Disease. They don't know how it will impact [them] and they don't know what's going to happen. I was clueless. Finally they

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told me “you have to get this surgery [for a] fistula, so that you can go on to dialysis.” So, “okay” again clueless as to what this would mean, and then they tell me “you have to do this now”, so I did and still did not have any idea what it would mean to be End Stage Renal Disease. When they finally told me you have to go and check into the hospital so we can start dialysis I was again “okay?” I had no clue and so I was kind of hit like a diesel running me over. I didn't have any idea what was going to happen and here they came at me, you know I'm in a chair, and they came at me with these huge needles. I was kind of “okay, didn't expect this.” So once they did this, I thought I better find out what's going on. So I went on the computer and looked up kidney disease to find out what to expect and to get some hopefully hard cold real facts about it. So that's how I was kind of introduced to it.

Justin

Honestly, we're just so appreciative of everything you've done for our ESRD community here in the Network. I wonder Jacque would you please tell us a little bit about the KCER LAN that you've been on this past year (and again that's the Kidney Community Emergency Response Learning Action Network). What does that mean exactly? And then what have you been up to?

Jacque

Oh Justin: the KCER LAN is, I would describe that as a vital project for the- not just for the renal community- but for anyone that it touches. It centers around being prepared for any kind of emergency. And that's what we were working on, getting vital information out to the kidney community and making them realize that there were specific things that they needed to do to be prepared in case of any kind of emergency. Because anywhere in [the] United States there can be an emergency at any time, and we centered on that. One of the things we centered on [was] having an emergency information card on your person all the time with your medical problems, that you're on dialysis. If you're unconscious for some reason, especially a renal patient, medical personnel need to know. If you have that emergency card, that's something that they can look at.

Justin

Jacque, I'm so glad you brought that up. You're right! That is so important. Now was that one of the tools you guys worked on this year?

Jacque

Yes, that was one that we were trying to get these emergency cards. And you can get the blank ones to fill in, that were developed by the KCER Team, on the KCER website. Another thing that they're really good about is getting you the information. They will give you an emergency checklist on the KCER website that tells you what you should have in your basic emergency go bag. These people will tell you everything you need to know on that website and the information is absolutely awesome.

Justin

Can you tell me a little bit about the process of making the cards, and kind of what goes on the cards?

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Jacque

Yeah sure! What we did was the KCER organization actually has the emergency information cards that they sent to us. And what we did was we got my clinic [to] help us and we got all the information on each patient name: date of birth, contact phone number, address, all of your basic stuff that type of thing; your primary care physician name and address and phone number; and your nephrologist name, address, phone number; your clinic name, address, phone number; emergency phone and your renal dialysis prescription ,what you have to have (you know the four hours of dialysis such-and-such). And the clinic helped us get all that information together and we just typed it into the lines, did their little form, typed it in line and the clinic laminated our cards for us so that they did not fall apart. And we gave them [out]. We had our emergency response lobby days and that was one of the things we did, was give every patient their information card.

Justin

Thank you. That that was one of the things I wanted to ask you about, and I'm sorry to interrupt, but is that how you envision patients are getting a hold of these tools? Like [are] the clinics handing them out, or how do you think patients can access this stuff?

Jacque

That was what we were trying to do. That was our main goal. The main goal was to educate and get this information out so we what we did was tell everybody, anybody that we came in contact with, the people on the LAN gave the emergency checklist flyers and the information about the cards and the KCER website address to anybody and everybody that would listen.

Justin

Well I want to also put in real quick, just because you mentioned that before-that you're absolutely right! That website is amazing! I've been there too and so to anyone listening who wants to access that [website] it's "www dot KCER coalition dot com", that's www.kcercoalition.com and I just wanted to highlight that, because Jackie all the stuff you guys make on there are so cool. I think you and I talked once that you could just spend hours looking there.

Jacque

I did! I went on one day just because I had time and I didn't have any, you know, background distractions or anything of this nature. So I sat down and I went into that website Justin and I was so enthralled with it that, when I turned around and looked at the clock I'd been on there for four and a half hours! And I wasn't bored! I was getting so much information and I was just amazed at how much work and diligence that went into creating something this absolutely phenomenal

Justin

I just can't thank you enough [Jacque]. Everything you do for us on the PAC and your work with the LAN. It's so impressive and when you think about the work you and others on the LANs are doing, just to improve the lives of those with ESRD; it really is, I'll be honest, just kind of breathtaking. So thank you thank you for being there and for all your hard work.

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Jacque

It's not just one person Justin, that's the thing. It's a group, it's a team effort and I am just really honored to be able to work with the two groups of people; the people on the KCER LAN and the people on the PAC. They're wonderful, I mean you know, they're great.

Justin

We hope you found it useful to learn more about the LANs. If you're interested in getting more involved in the dialysis community, please talk to your clinic social worker about joining the Network's PAC. Also, please keep a lookout for the next episode in the Dialysis Life Podcast Series. Thank you for listening. This is Justin Carr, for Network 15. Take care.