

## Title

**After surviving kidney cancer and receiving a living donor kidney transplant, Darryl donates his experience in return – as a mentor and guide.**

## Summary

In our last episode, the first of several episodes celebrating National Donate Life Month, we sat down with Jennifer Martin from the National Kidney Foundation and learned about “The Big Ask, The Big Give”, a program dedicated to helping people with chronic kidney disease find their living kidney donor. In this episode we meet military veteran Darryl Shaw, a kidney cancer survivor who also served multiple tours of duty. Darryl’s family members helped champion a successful campaign to raise funds for a kidney transplant, funding that helped his eventual living donor complete the initial compatibility tests. Darryl now volunteers as a mentor with programs such as “The Big Ask, The Big Give” from NKF, sharing his experiences and giving encouragement. He can offer perspectives from the point of view of an African American who received a kidney from a Caucasian friend and colleague, as well as being someone who opted for home dialysis and overcame many medical challenges. Darryl is now studying for his master’s degree in Pastoral Counseling, and he plans to continue in service to the kidney patient community.

With host and series producer Rolf Taylor.

Resources mentioned during the podcast:

April is National Donate Life month [www.donatelife.net/ndlm/](http://www.donatelife.net/ndlm/)

The Big Ask, The Big Give, NKF [www.kidney.org/transplantation/livingdonors](http://www.kidney.org/transplantation/livingdonors)

The National Foundation for Transplants [www.transplants.org](http://www.transplants.org)

Mighty Cause [www.mightycause.org](http://www.mightycause.org)

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TRANSCRIPT

Host: Welcome back to Kidney Transplant Conversations, our regular podcast, featuring discussions with healthcare providers and kidney transplant recipients sharing diverse experiences and exploring quality care delivery. I'm your host and series producer, Rolf Taylor. Kidney Transplant Conversations is underwritten by Veloxis Pharmaceuticals Inc., all views and opinions expressed in the podcast reflect those of the participants and do not necessarily represent the views and opinions of Veloxis pharmaceuticals Inc. or the producers.

Last week, in the first of several episodes celebrating National Donate Life Month, we sat down with Jennifer Martin from the National Kidney Foundation and learned all about The Big Ask, The Big Give; a program dedicated to helping people with chronic kidney disease find their living kidney donor. One of the things we learned from that discussion is that asking is awkward. And so, one of the first steps to success is finding a champion who's comfortable asking people to share your story. We also learned that your potential donor may surprise you by being closer than you think, they just needed to hear your story. And one size does not fit all. So, learning about lots of options allows you to figure out what fits with your situation and with your culture. Jennifer introduced me to transplant recipient, Darryl Shaw, who joins us on the podcast this week to tell his story. In fact, he shared the kind of detailed experiences that really help us understand why it's difficult to make that "big ask." And yet, it's a challenge that can be overcome with the right approach. Darryl is a veteran with many years of military service and with some time in DC with the federal government, including the White House. I asked Darryl to start by sharing with us some of the places he served and how he came to learn he had a kidney condition.

Darryl: I started in Germany, participated in Desert Shield, Desert Storm. After Germany, I came to Fort Bragg, North Carolina, where I was a paratrooper. (Then) I had my first assignment in Washington, DC. From there, I went to Korea for two years. I went to Saudi Arabia for a year. In the White House for three years, under the Bush Administration. We went to Hawaii, where I served as a Battalion Commander. After Hawaii, we went back to Washington, DC, and from Washington DC, I went down to Army Central Command, which was in Atlanta at the time. And then we moved to Shaw Air Force Base in South Carolina, and that's where I retired. We really enjoy being in the DC area, it just has a different buzz to it. And the fact that I was there for nine years off and on and spending time in the White House has just given me a different perspective on politics and how things are accomplished, even for our military or in the Department of Defense.

We would've stayed there, but because of the Army, we ended up here in North Carolina. My son was in high school here. And so, we elected to retire here in this area. And the interesting part of all of this is that I was diagnosed with kidney cancer in 2007 while I was serving in Hawaii. We believe it may have been as a result of exposure to some chemicals of some form when I was serving in the desert, because I do not have the genes that predispose me to kidney cancer. And so, I battled with it from 2007 to about 2017. And all of this time, I was still in the Army and still when I retired working for the federal government. I underwent a lot of surgeries, partial nephrectomies, to remove the cancerous cells. And the challenge was that it was bilateral, going between both kidneys. And in September 2017, we lost the battle with the right kidney, and so that was removed. And that's how I ended up on dialysis for about two and a half years. I did home hemodialysis, which caused me to learn a lot about the process of dialysis - of hemodialysis - and with the lab work, preparing my own solutions cannulating myself. And that's where I met Dr. Hladik, when I first went into dialysis and the different modalities, and he highly encouraged me to go into the home hemo. I think I was one of the first patients here in the Fayetteville area to do home hemodialysis. It's about an eight-week training program that you have to become certified to do that, because of the nature of dialysis and the risk involved with it. The home machines are less demanding on your body. And it also allowed me to have flexibility to continue to work, which was very important to me at the time, to maintain some sense of normalcy in my life. And so, we went through that for about two and a half years because after they removed the right kidney, we knew we needed to remove the left kidney to remove all traces of kidney cancer. So, about six months later, they removed the left kidney - and I had to be cancer-free for at least two years before I can be eligible for a donor. So, at the two-year mark, I was not able to receive the transplant because COVID presented itself. So, during that time, we created a fundraiser through the National Fundraiser for Transplant Organization, and my wife was very instrumental in that.

Host: Darryl set up his initial fundraiser through the National Foundation for Transplants. You can find them at [www.transplants.org](http://www.transplants.org). And his initial fundraising page was hosted by Mighty Cause, that's [www.mightycause.org](http://www.mightycause.org).

Darryl: We used Facebook and we used that donation page to solicit donors. In the Chapel Hill, they have a very, very robust donor program. Because it's very difficult to ask someone to give you a kidney. You're asking someone to give a vital part of their body to you. You know, we're born with two kidneys, they give

up one, you can survive off one, but you really don't want to have that kind of conversation in asking someone to donate that to you. And so, it's best - what we use, we just put it out there as a fundraiser. In Chapel Hill, they helped me create the page and the National Foundation of Transplants, they were very instrumental in creating the landing page to tell my story. Then, we gave it out to friends and family, and we also provided the number for the transplant coordinator at Chapel Hill. And so, whoever wanted to donate, they were able to contact the transplant coordinator, without any knowledge from me of who was doing that. And I guess there's a sense of, I don't want to call it guilt, but it's a sense of again, you're asking someone to make a pretty, tough decision, especially if they're young. Based on their age, if they have children, they may want to keep that organ in case one of their children or family members end up in the same situation. So, I had a few people from my organization where I was working, because at this point, I'm working for the federal government that wanted to donate. It was a young lady. She is Asian American. She became a good friend of mine, one of my subordinates, and she wanted to donate, but she had three children. And she was relatively young, in her forties. And it really touched my heart and taught me a lot about the nature of people, but I did not want her to be a donor for me. I did not want her to go through the process of anything of that nature, even though she was willing to do so. So, it really humbled me that she was willing to do that for me, and I was her supervisor. But my actual donor is a white American male. He was an army buddy, over 22 years ago. We were next door neighbors in Fort Leavenworth in Kansas City. And we established a - our families connected, our wives connected, our children connected, so we considered ourselves brothers. At the time, we did not know the purpose of our meeting. Some 20 plus years later, we realized there was meaning behind the reason why we met and why we were next door neighbors for over a year while we were attending a school out there. So, when his wife found out about what I was going through, without any hesitation, Jim volunteered to be tested. And to the best of my knowledge, he is the only person that was willing to be tested as a living donor. And it just happened that we matched, at least the initial matching process with the blood. And then, we went through the further testing of the antigens in our blood, and we were still a match and we set a date for the transplant.

We did a session with potential recipients and potential donors to share our story, because we felt we were quite unique, being that we were a different genetic background. And there are a lot of people that are hesitant to do transplants, and there are a lot of people hesitant to be donors because of the cost. So, Jim and I were fortunate, he's a retired army officer as well, so he had Tricare. And plus, through my fundraising, I was able to pay for some of his medical costs when it

came to testing and everything else. Plus, Jim owned his own business. So, he was not concerned with the leave issues that may arise.

Host: Since his transplant, Darryl has become actively involved in supporting others through the transplant process, including volunteering as a mentor to people who find themselves in the same situation as the one, he experienced, needing to find a living kidney donor. I asked him to talk about The Big Ask, The Big Give program, and how it can help donors and recipients find each other. As a donor recipient, Darryl has also discovered great satisfaction himself, intonating his experience to as many people as possible as a mentor and guide. As he points out, this provides for a vital need that most doctors cannot fulfill because most doctors have not themselves experienced the physical and emotional impact of needing and having a transplant.

Darryl: The Big Ask program is the value of using social media in various outlets to seek a donor. And I also asked them to potentially interview Jim for this podcast because he can tell from the donor perspective what he went through and everything. I could share with you that when we were delayed for the procedure, Jim was pretty upset because he was ready to go. I think he was a little more upset than I was, that we were pushed off for a period of time. You know, it was the onset of the virus and a lot of unknown variables. And I also had some challenges with my fistula. I underwent quite a few challenges with the dialysis process. And so, we felt, the sooner, the better. And it also caused the hospitals to change the immunosuppression drugs they give you during your surgeries. They did not want to completely wipe out your immune system while we were undergoing the outbreak of the coronavirus.

Host: The Big Ask, Big Give program, it has a matching system, doesn't it? So that people who've experienced the journey can share their experience with people who are thinking about it.

Darryl: Yes. Going back to why I'm in school, as a result of my journey, I wanted to help someone else, especially kidney patients, and be their advocate, because you need an advocate. You really need to have an advocate. And so, I try to serve as an advocate for others by sharing my story and letting them know the possibilities because there are a lot of kidney patients that I come into contact with that are really hesitant to pursue a transplant, and they're really afraid to ask someone to give them a transplant. My perspective, I did not realize how sick I was, for those 10 years I mentioned and plus the three years on dialysis. And even going through the transplant and everything else, I really did not know because our bodies adjust

to our current state, and my feelings, the amount of energy, my skin color, I just tell them it, it is just worth giving it a try. It requires a lot of discipline on the backside with the medications and everything else, but I still believe the benefits far outweigh the risk in pursuing a transplant. I go to LabCorp's once a week for my blood draw, and I've run into patient's post-transplant that are struggling with their medications, that are struggling with the requirements for the blood draw, that are discouraged at times. And I try to encourage them, just by being a living witness and being a coach as well. They call me, they ask me questions about medications and how do I feel at different points in time? And I'm able to share what I've learned from Dr. Hladik and from my personal experience. And even Dr. Hladik, he tells me that the challenge for doctors, they have not been through the actual feelings of a dialysis patient or even a transplant patient. A lot of their knowledge is based on theory, research, but to actually live the process, most of them have not lived the process. And so, they have a very difficult time encouraging patients to pursue certain things because of the lack of trust of the medical system. And so, they'll have these doctors speaking to patients, but they don't have the real-world experience of it.

Host: And, of course, we really don't have a healthcare workforce which mirrors our population.

Darryl: Yes. Very True.

Host: So, for example, in particular, I think for African Americans and for Hispanics, we have disproportionately fewer doctors in those specializations.

Darryl: Yes sir.

Host: And people do benefit from receiving care from someone who looks like them.

Darryl: Yes.

Host: One of the significant health disparities that we see in kidney transplant is the relatively lower access to transplant for African Americans who, as a result, tend to spend relatively more years on dialysis. There are multiple reasons for this. The significant factor is that there are relatively few African American nephrologists and transplant surgeons. And this can be a barrier to cultural understanding, rapport and trust. I asked Darryl if he finds this to be something he can help overcome as a mentor?

Darryl: Yes, because we have some cultural similarities and understandings about the lack of trust and even the socioeconomic portion of it because a vast majority of the patients end up on dialysis by way of diabetes. And so, there becomes a concern within the transplant community that if you are not compliant with your diabetes care, how well are you going to be compliant with the transplant care? And I mentioned the word discipline, and I guess some of my discipline came from being in the military, that allowed me to be on top of everything that I needed to be upon and watching my labs and watching my scores. But there's always a huge concern about the discipline of the patient and whether or not they will be disciplined enough to take care of their kidney. Because post-transplant, there is still a lot of things that you have to be aware of as far as your diet. There's still some other restrictions that take place to ensure the efficacy of your medicine is at its best.

Host: So, what encouragement does Darryl want to give to people who are going through the transplant process, and then wanting to make sure that they thrive long after the actual transplant takes place?

Darryl: Having the faith, having the trust, having the confidence, that medical care and the doctors are doing their best. They're doing their best to help you. There are a lot of side effects that they may not share with you up front. And I highly encourage people, also, to pursue the home dialysis process, be it chemo or periodontal, only because it causes you to learn what's going on, how to take care of yourself better versus, a lot of patients that I saw, they just go in there, they get their treatment, they don't understand what's happening as far as the blood draw, the settings on the machine, and they just put their arm out or their leg out, wherever their access is, they go through the process and they go home, and they never take the time to ask the questions about, you know, why are we doing this? What's going on? You know, why am I cramping? Why do you have to take so much fluid off of me? And so on and so forth.

Host: It sounds like you've worked really hard at being your own advocate.

Darryl: Yes, sir.

Host: As well as letting someone else advocate for you.

Darryl: Yes.

Host: I think that, you know, I spoke with somebody else who'd received support from The Big Ask, The Big Give program amongst other programs, and he was saying that it had really encouraged him to find a champion who could ask potential donors on his behalf, because he felt uncomfortable asking directly. So, in the end, I think it was his cousin who became the champion, got everything organized, and crucially, she did all the social media, and he said he was too old to do the social media. He didn't even have a Facebook account.

Darryl: And it's tough, especially when you're, if you're on dialysis, it's very, very difficult to have the mental energy and emotion to do the big ask. I would say my wife is very instrumental, and her friends. They were my board to advocate for me, to tell my story and to manage my national foundation page. And I was just fighting to survive while they were taking care of that for me.

Host: So, what I'm really hearing is how important it is to get organized.

Darryl: Yes. And most transplant coordinators, I would assume, they will walk you through that process. I was talking to a patient recently considering a transplant, and I asked him to make sure you talk to the transplant coordinator about the resources that are out there, and just the process that you have to go through because the sooner you get organized, the better.

Host: And a lot of transplant centers also have a financial specialist?

Darryl: Yes sir.

Host: That can help with all of those things.

Darryl: Yes.

Host: There's a lot of resources out there and it seems that as a result of policy changes, there seem to be more resources now than even just a couple of years ago.

Darryl: Yes. So, I was fortunate enough through Dr. Hladik and there is another doctor that does a lot of this, I went to the ceremony in Washington, DC when President Trump signed into legislation about the donor process and the medication, really, post-transplant. So, I was fortunate enough to be there. And I've also witnessed some recent changes. Before Medicare, after post-transplant, Medicare would stop after a certain period of time paying for your meds, which is very challenging. The fact that I had my Tricare for my military service, and now I still have the



Medicare, it kind of alleviates a lot of the cost for me. So, it makes it more manageable. Because I have asked, what is the biggest reason why transplant patients do not succeed? And they said, the costs of the medication. They can't afford it. And so, they stop taking it.

Host: And there is assistance available for medication cost, sometimes from the company, but all of these things are another administrative step.

Darryl: Yes.

Host: So, no doubt, a lot of help is left on the table because it's a bit of a maze just figuring everything out.

Darryl: It is. And as you mentioned, you really need to have a coach and an advocate to help you navigate those processes.

Host: So, if Jim was listening now, what would you say to him?

Darryl: Thank you for another chance at life. Thank you for giving me a chance to make a difference, to share my story and giving me the ability to encourage someone else. Obviously, we stay in touch, now. We have an anniversary. We've had our first-year anniversary and this May, we'll have our second anniversary, and we'll meet somewhere with our wives, and we'll go have dinner, spend time with each other and just catch up on how our children are doing, our grandchildren are doing, and just sit and have a great time.

Host: And now you are - did you say you're studying pastoral counseling?

Darryl: Pastoral counseling. Yes, sir.

Host: Do you see a continuation, then, from your journey through transplant into pastoral counseling?

Darryl: Yes, definitely. Without a doubt. Without a doubt.

Host: And where do you think that's going to take you once you finish your studies?

Darryl: Well, so there are a lot of options. One may be serving in a hospital environment. One may be providing pastoral counseling through my local Christian community.

Host: Isn't it kind of magical when people talk, how these things change in our minds. When we talk, we process, we work through things and, really, talking is the "special sauce" that does that?

Darryl: Yes. Because for me, I knew I had the kidney cancer, I knew I was doing the partial nephrectomy, I knew my GFR was getting lower, but I never thought I would be on dialysis. And then when I was told that my left kidney was failing and that I had to choose a modality for dialysis, that was really tough. That was very, very difficult to accept. It was very emotional.

Host: Because this is what life is bringing you. Down the road, you've got to accept it.

Darryl: And then my perception of dialysis was way off, you know?

Host: Really?

Darryl: Oh, yes. When I hear the term dialysis, I was like, oh, it's over. I'm like, oh man, I'm done. And again, I have been dealing with this cancer in my kidneys for 10 years, but it's almost as if I never thought I would be in that position. You know, and they come at you with so much information so quickly about choosing a modality. Do you want to do this way? That way? What you should do. And I had a fear of needles.

Host: Oh?

Darryl: Because they're quite large. And so, I had a lot of fears going into dialysis.

Host: But it sounds like what you would say to someone else in a similar situation, when all that information is coming at you so fast, it would be to not be passive and not just let all the decisions be made for you, but to really do the extra work to understand what's going on, so you can make an informed decision.

Darryl: Yes. Even if you have the ability to just talk to someone else because, you know, they're coming over with a card and saying, hey, these are the three modalities, which one do you want? Like, I don't know. And so, what Dr. Hladik tries to do, he tries to get me to talk to patients before they get on dialysis. To try to talk to them about the modalities and the stuff that they're hearing, that's coming at them so quickly, to talk to them about the experience of being in a dialysis center, to be able to talk about the advantages of being able to do home hemodialysis, because

they will tell people, you know, you can work while you're on dialysis, but it's very, very difficult. It's extremely difficult.

Host: But also, dialysis isn't the end of the road.

Darryl: Yes. It's not the end of the road and it's not the death sentence that I gave myself when I was told I was going on dialysis.

Host: Right. And here you are!

Darryl: Yes. It was to the point where I called my HR people at my job and told them that I'm resigning. And luckily, they had enough faith in the process. They said, don't make that decision at this time. They said, give it time. No, don't do that. And all of this was happening in a hospital environment, you know? So, I probably was on quite a few medications at the time and probably didn't have the clearest thought process, but I was calling, making decisions, and it was not a healthy thing to do.

Host: Well, I think that's something else. When you have an advocate, you have someone as a sounding board. When you're in kind of the storm of information, decision making is difficult because everything seems to be moving around, but at least when you can have a conversation about it, it's easier to prioritize, it's easier to get some clarity.

Darryl: Yes sir. And that's why I just try to give back from my experiences, to try to encourage someone else.

Host: So, someone coming to Big Ask, Big Give program, they get potentially matched with you as a mentor?

Darryl: Yes.

Host: They're a very lucky person!

Darryl: Oh, yeah. I would love to do that. So, yeah, because I do it now, and I'll continue to do that for all patients. And I guess I call it when you're diagnosed with a terminal disease, to be there and talk to the family and talk to the patient. Because the discussions the patient may have with their family versus someone else can be totally different. Sometimes, as patients, we tend to - we may go to both extremes. One, is going to be okay, or two, this is over.

Host: Do you feel like sometimes the information that you want to share with the people closest to you, but you want to protect them as well.

Darryl: Exactly. And you have this thing of, I don't want to be a burden on you. I don't want to disrupt your life. And so, you start trying to make decisions that you think are going to be in the best interest of those around you, or those close to you. Some may say, I don't want to get a transplant because I don't want to be a burden on someone else.

Host: And sometimes, the family members will say, we are here to carry that burden.

Darryl: Yes. And then, when you see them going through it as you're going through yours, you'll say, man, this is just too much. It's just too much. Because it is a toll on the family. Because there are a lot of things, like I mentioned before, there are a lot of things that can go wrong with dialysis and that whole process, and I probably experienced them all.

Host: But you are kind of a survivor several times over, aren't you?

Darryl: Oh, yes, yes, yes. There are those that call me a miracle, that I'm even able to have this conversation with you today. Because of some of the things and the hiccups that we experienced along the way.

Host: Well, it's such a pleasure to talk with you. And I feel very humbled. And I really appreciate you sharing your story and sharing your story with listeners to Kidney Transplant Conversations, really appreciate it.

Darryl: And as I mentioned before, if there's anything that you need assistance with or any way I can help, I'm here for you.

Host: And we are very grateful to Darryl for his service, for sharing his experiences today, and for continuing to give back to the transplant community as a mentor with The Big Ask, The Big Give program. And thanks everyone for joining us today. And once again, thanks to our underwriters Veloxis Pharmaceuticals. Join us next time when we'll be hearing from another transplant recipient about how they made that big ask. For now, take care and be well.

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