



One-on-One with Donna Sweet, M.D., AAHIVS

The woman “behind the curtain” in Kansas

Interview by [Jeff Berry](#)

Jeff Berry: Please tell us a little bit about yourself.

Donna Sweet, M.D.: I have been doing HIV work since 1983, when I saw my first case in Wichita, Kansas, and I’ve been the principal investigator for the Mountain Plains AIDS Education and Training Center [MPAETC] since 1988. During this period, I spent a great deal of time stumping rural Kansas trying to make life livable for the people who were there because Kansas was not terribly tolerant, as many states weren’t. I spent a lot of time going from small town to smaller school system talking about HIV—what it was and what it wasn’t—and trying to do prevention work. It’s interesting that Kansas, which is not at all progressive or liberal, was one of the better, more progressive states when it came to things like HIV/AIDS education. There was a Governor’s AIDS Task Force that I was on—as a result of that, the school board mandated that HIV education and prevention messages had to be in all school districts in Kansas. That lasted until about 1997 and a much more conservative school board got rid of that mandate. In fact, we went, in the late ’90s or 2000, to a much more abstinence-only based sex education, which has been problematic.

There are 105 counties in Kansas and I’ve been to most of them, especially any that had a public health department or a hospital, doing HIV education. As a result of that, my name was the one people remembered if

they did find AIDS cases and because of that, my clinic, my team, takes care of a little over 1,250 HIV-infected patients. We cover, literally, over three-quarters of the state of Kansas—my clinic is in Wichita. As a result of that, we see many people who live in very small towns. We take care of them and get them enrolled in the system, and then see them in the outreach clinics, so people don't have to drive the 200-250 miles it would take to get into our system if they physically had to come to Wichita.

JB: What do you think are the lessons learned in your experience working in Kansas all these years that might inform some other rural communities across the country?

DS: In rural states like mine, you don't get anywhere near the amount of money per capita for HIV patients that big jurisdictions like New York and L.A. do. We have divided Kansas into nine case management AIDS areas with a case manager in each of those regions, and we have an outreach case manager who goes with me to each of those clinics, so that all the paperwork can get done, the meds can be had, and whatever it takes is done to get people care. With physicians, our focus has been to try and get them to routinize testing, to find the people in Kansas we don't know about. I'm continually frustrated that a great many patients, 40–45%, just like the national average, come into our system sick, quite sick, and that just shouldn't happen anymore. So we spend a lot of time trying to get clinicians to routinize testing, to understand the 2006 CDC Guidelines for routinization of testing which promote at least one HIV test for every American between the ages of 13 and 64, which have largely gone ignored in many places.

What I tell them is that you don't have to accept the responsibility of treating these patients—that's what frightens many clinicians; they just don't know anything about HIV/AIDS care. I tell them this is how you do the test, this is the opt-out system, you don't need separate informed consent. Find the patients and then call me. Call me or call somebody, but we'll make sure we can help you link that individual to care.

About 45% of the people who come into my system of care have no visible means of health care coverage so we can get them Ryan White, I can get the labs done through the system that I have, and I can give discounts. But it's very different if you're ordering one CD4 count, one HIV genotype, and one viral load out in a small system. That reference laboratory is going to charge clinicians a fortune to get that test, and then if the patient doesn't have the resources to pay for it, the clinics are looking at a big red hole in their budget. Small town physicians are small businesses and they're struggling right now, especially in primary care.

JB: So it's not only fear or lack of awareness among patients or potential people at risk, but also among the providers?

DS: I can look at anybody and say, "He's got a cough, he needs an HIV test; he's got a fever, he needs an HIV test," because I see it every day. But if somebody's out in Small Town, Kansas, who doesn't really think about this because he or she doesn't see it, it'll be the fifth thing on their differential, and that's why it gets missed as often as it does.

In rural states like mine, you don't get anywhere near the amount of money per capita for HIV patients that big jurisdictions like

New York and L.A. do. We had a case not too long ago that shows that serendipity works, I guess. A young man was in the hospital with pneumonia, and wasn't getting better. But the reason I got contacted is because there was an inadvertent needle-stick. A nurse stuck herself when she was drawing blood on him. We've encouraged rapid testing in that situation, which this hospital was doing, and the gentleman was HIV-infected. He would not have come to our attention as to why his pneumonia wasn't getting better because he was being

treated as though he had community-acquired pneumonia, and he had bad pneumocystis. So it was an accident, a lucky accident, that he was even found to be HIV-positive before he got even sicker.

JB: I was reading through some of your Ryan White testimony, when you were talking about the Girl Scout-style fundraising and what you have to do to keep your clinic afloat. Is that typical?

DS: I think all of us participate in one way or another, be it ASOs [AIDS Service Organizations] that are doing AIDS walks, or those who are contributing to the care of the patients. Ours is largely in part because ADAP in Kansas doesn't cover anything but anti-infectives and antivirals so, especially since my patients are living longer and getting everything from diabetes to hypertension to lipid problems, there are lots of other medications that they need that are also expensive. I also think it's important—and all of my peers and people I've worked with for years all across this country are doing this—to be involved to some degree in some sort of social activation of their community, and fundraising is one way to keep people aware that it's still out there, that we still have a problem.

JB: You also talked about explaining to physicians about the opt-out testing and then having them call you—I'm just wondering, is there someone like you in every rural state?

DS: There really is. For the most part, there's a person or group of people that does it in most rural states.

JB: Due to the flat funding of ADAPs, do you foresee waiting lists becoming a problem in your state?

DS: No, but I was talking to Dr. Kristin Ries and there is a waiting list in Utah now and apparently, if there isn't one in Nebraska, it's about to start [Nebraska had a waiting list of 75 as PA went to press], so, as I'm sure you know, there's an increasing number of states going on that waiting list.

JB: So the patients you treat who are insured—are they able to get into the co-pay programs of the companies? Do the providers know about them?

DS: Well, we certainly do. I think most of us who have many patients, it behooves us to figure out how to get some help, because quite frankly, sometimes those insured patients, with the way co-pays are on some meds, people think they have better insurance than they do until they have to use it. If you're taking medications that are costing a couple thousand a month, especially if you have to take two, three, or four different scripts, your co-pays may end up being in the hundreds per month. So yes, using some of these newer ways the companies have of helping out with co-pays—\$200 every month on this pill—I know you're aware of those programs, they can be quite helpful.

JB: That's good to hear. And the patient assistance programs for the uninsured are kind of the same thing, I would imagine.

DS: Yes, that's what our case managers and social workers are always on the lookout for. In my little office, there are five of us who are providers—two nurse practitioners, a PA [physician assistant], my junior partner, and myself—we're all credentialed by the AAHIVM [American Academy of HIV Medicine] as HIV Specialists—and we employ one full-time person who does nothing but patient assistance paperwork.

JB: In terms of stigma, can you talk a little bit about how that's a deterrent to care or what might be a way to overcome it?

DS: Boy, I wish I could figure that out. I'm not sure it's just the rural nature of communities; sometimes communities in big cities can be fairly closed. It's still a homophobic society in many parts of the world and there are many of my patients who I think avoid getting the care they need, or the tests they know they need, until they just can't deal with it anymore because they don't want to be "found out." And the "found out" is not so much that they have HIV or AIDS, but it's that they're gay. There's still a very large amount of that that goes on. I have a number of people who don't ever want me to leave my name on their phone system because somebody else might pick up their calls. That's the downside of a state like ours. Though I take care of a fairly large number of non-HIV-infected people as well, people jump to the wrong conclusion and sometimes to the right conclusion. We have people in many of our smaller rural towns where there is a local pharmacy, but there's a pharmacy in Wichita that's worked with me for years and years. I have no interest in it financially, but it's just always been wonderful in helping my patients. We have a lot of people in small towns who have this pharmacy fill their prescriptions and mail them to their home in a plain brown wrapper, because they don't want to go to their pharmacy and pick up their zidovudine or whatever when the pharmacist would know what their diagnosis is.

JB: Wow. Yeah, I wouldn't know the answer to that one either, but I think just shining some light on it might help.

DS: It isn't as bad as it was 10 years ago and it's certainly not as bad as it was 20 years ago, but you know, I live in a land of Fred Phelps—I'm sure you've heard of Fred—and he's still active in our part of the world.

JB: Oh, yeah, I remember, I was in the march through D.C. in '96 and they were all standing there and we marched by and got the crowd going, got them all to chant, "God doesn't hate"—it was fabulous, we shouted them down.

DS: That was good.

JB: So what keeps you going? I mean it sounds like you've got a lot going against you.

DS: Oh! I love my patients, I love what I do and there's always something to work to improve. The people in my clinic, we've all worked together for a great long time.

JB: So do you have any words of advice for someone else living in some rural part of the country, patient or provider?

DS: Well, I would say find out who the local treater is and when we say local, in places like Kansas, I know people who go to dinner and drive 100 miles because that's the only place if they want a nice restaurant. Find out, through the various ways, you can do it through AAHIVM—they have the website that has credentialed providers and there are credentialed providers in some very small parts of the world if you just look. You can go through the National Clinical Consultation Center, which is part of the AETC network. You can find an AETC that covers every state.

JB: Yeah, that's really important, to find a provider. So that's interesting—driving 100 miles for a meal isn't uncommon. That kind of puts it in perspective!

DS: If you ask what is one of the major problems in rural America for access to health care, not just HIV, but any health care, it is transportation, because so many patients don't have a good car. That's one of the reasons we started doing the outreach, going to the communities, because it takes a pretty decent vehicle to drive 240

miles both ways, plus that's going to be a whole long day if you're sick. A lot of people don't have access to good transportation and there is no public transportation in a state like Kansas.

JB: That's a good point. Is there anything else you'd like to say?

DS: Well... other than that I love taking care of my patients, it's an exciting field and we just have to continue to encourage young people going into health professions—physicians, nurses, pharmacists, dentists—to really help take care of this population. It's growing and I would like to see AIDS mainstreamed enough that people would feel comfortable taking care of AIDS patients. Part of it is the science—it is difficult to keep up—but part of it is still that the smaller you are, the more likely it is that somebody's going to look askance at you if you have an AIDS patient in the waiting room sitting next to them and they're there for their well-baby check or their hypertension. That's something that's kept clinicians, even interested clinicians, out of the field, because they're fearful of what the community will think. They certainly have to make a living, so they can't disregard the feelings of the entire community to take care of a few. I think we really need to continue to de-stigmatize the disease everywhere.



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