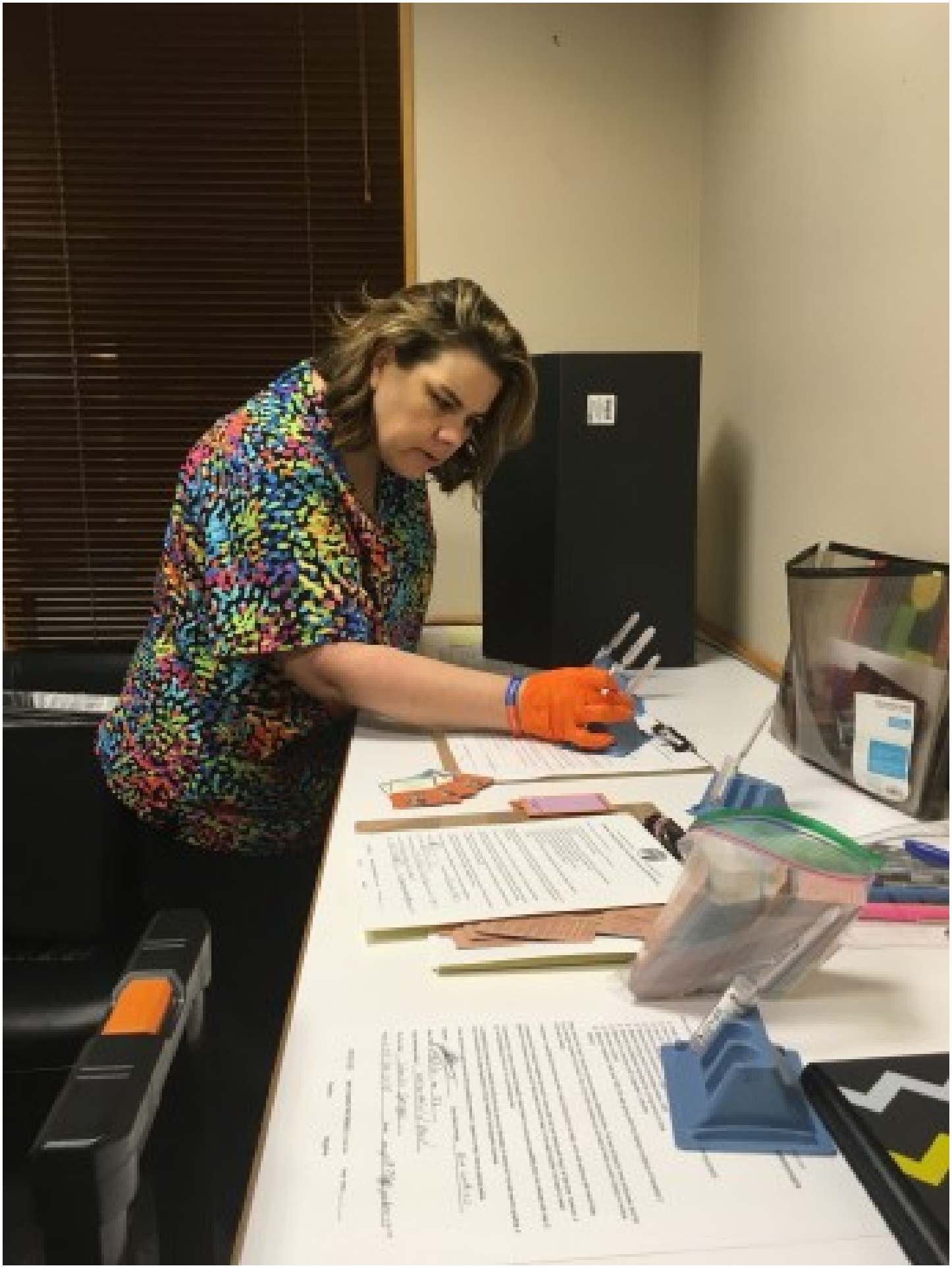
100 Down 3 Million To Go Rural Hepatitis-C Testing

June 7, 2017 By Carleen McGuffey



James and I arrived at our testing location Friday evening. The parking lots were full, lawn chairs unfolded, tents pitched, news media on hand interviewing some of the hundreds of clients waiting

to get free medical services.

We were greeted by several people in the United States Public Health Service Uniforms. My son is a Marine and I'm a member of our local VFW so I feel a bit silly that I didn't know the USPHS is a branch of the Uniformed Services. One lady said they are, "The Few, The Proud, The Forgotten."

We usually set up the day or evening prior to a clinic but these fine folks from the USPHS were actually camping in the school, on the floor, on makeshift cots, and sleeping bags, so we dropped our supplies and headed out.

Clients start receiving numbers around 3am; they often appear disheveled, wrapped in blankets, red eyed, and tired. One lady said she had a taxi drop her off and she literally slept on the concrete parking lot. The people don't come for fancy cosmetic procedures or expensive root canals--they come because the pain is more uncomfortable than hitching rides and sleeping on the ground.

We set up a crude lab/counseling/testing area of sorts; we use what we have. Privacy is scarce, although we do everything we can to make our clients feel valued, loved, and respected by taping together boards, and posters to provide a little dignity. This is especially helpful when counseling a client who is positive. Hep C is still highly stigmatized, and some of these people, though poor, are also proud.

I make sure my kids are present, within earshot, eyesight, and safe. James and I decided that we wouldn't allow this work to separate our family, but rather bind us yet closer together. We go over the rules again and again. We also pray for each other to be a blessing and save lives! You know, kids have an incredible ability to understand the urgency of suffering. Why can't all the other millions of Americans just see it like my 5 year old: "Mom how many positives? We saved lives! Can I test people? What time is lunch? What can I do to help?"

We stand before hundreds of clients and pass out Health Advisories from the State of Tennessee sharing that hepatitis C is a public health crisis, that hep C rates are growing, and that we are here to help. No judgment. I am careful to never lock eyes with anyone as I share risk factors at the top of my voice so everyone can hear. "Ever injected drugs, even once…" Even though I work hard to never stare directly at clients it's hard not to notice them squirm or express shock as we share certain risks they never considered….using a straw, dollar bill or another device to snort may be enough to break a capillary and transfer the virus, tattoos in an unclean environment, inoculations from aPedo-Jetgun…. There are usually a few brave souls who ask questions. "Why should all baby boomers get tested?" "Is the medicine still $1000 a pill?" "I was positive, but then I was negative, should I be tested?" "Is this about that one drug I keep seeing the commercials for?" We smile a lot, share what we know, and keep things light and welcoming. It's important for us to convey our sincere desire to help right where people are at, nothing more and nothing less.

These people aren't dumb, just poor. You know how when a person loses one sense, the others are exercised more and become particularly strong? Well, I almost feel like some of these people have so little, yet they've learned to compensate, and adapt. It takes a keen sort of intuition, wisdom,

and perhaps a dash of spirituality to survive on next to nothing. Most know exactly how we feel before we even speak--it conveys, you know? Your heart conveys as to whether you are here to serve, love, and heal or just judge, enter data and punch a clock. I value every client that we see as though they are my own self, child, or spouse because they could be one day, or they have been in the past. I feel a tight kinship to these precious souls, as I too have hidden my hep C status, drug use, shame, and poverty from the world. I remember clearly that the only people who ever helped me were ones that loved me through my problems or perhaps loved me a little more because of my problems. It's true that many people bring shame, disease, and isolation upon themselves. I feel for the moms whose hearts have been broken, wives and children who have been betrayed, and communities frustrated with crime...and yet God has given us this unique opportunity to love this person because they need it, not because they have earned it or even deserve it. It's this kind of love that really heals. Some of these souls know they have behaved poorly, burned bridges, broken laws, and alienated everyone, they know. They know that YOU know it too, but if we still reach out, smile, love, and serve generously we can all be transformed. It changes us when a person sees past our faults, to our heart, our needs, and deems us worthy despite the brokenness.

The test takes about 5 minutes so we use that time to share information about the process--that it is a screening--and if positive the client will need follow-up, we explain that there is an incubation period, we share hep C basics as we gather info and use that short time to educate and answer questions. Clients come back anytime after 20 minutes for results. We have decided that we will spend as much time as needed with positives, no rush. Ever. We calculate what a client can hear after learning they are positive...not too much, but just enough. We have put together resources and literature, again we carefully consider what may be thrown on the floorboard and what needs to be read.

Linking clients to care makes me feel like a bit of a contortionist. I reach there and stretch here, always learning, listening and ready to change as new resources become available. I consider obstacles and how to overcome them. Some obstacles are created for average Americans but these rural situations aren't always typical or average. It may be that some of my clients will never get the recommended number of labs, or a suggested biopsy. AASLD guidelines are great for most Americans, but we are thinking about how to eliminate as many hurdles as possible to see our clients healed and educated. It's a challenge that demands we stay malleable and creative.

I have to remember that as a patient advocate, my job is to serve clients, not appease every naysayer and finger-pointer who stands on the sidelines wagging their fingers or shaking their heads because of this and that. Patients, healing, love, the relief of suffering….I have to stay focused. Did I mention that my priorities lie with patients, healing, love, and the relief of suffering?

I am constantly assessing my protocols and plans. What works? What doesn't? How can we do this better? Will this relieve more suffering? There are many adversaries but also many doors of opportunity, and we are just risky enough to walk through them.

Over the course of our weekend, we tested 91 clients and had positive rates several times the

national average. Some of our clients were from the USPHS, volunteers, and providers. This is much more than engaging a few people from the community--we met with the local AIDS non-profit, several providers, a few who work in prisons and on reservations. We talked to the Surgeon General of the United States who dropped by to check out the clinic and her crew. She was very interested in our work and listened intently as we shared with her our rates, thoughts, and experiences from the field. We reminded volunteers that universal precautions are important. We want to permeate the entire community with hepatitis C education, awareness and services. It helps to test 100 people but if we can leave a sustainable hep C voice within the community, now that is impact!

Now, several days later, I am back home cuddling with my children, tweaking the process, updating forms, inputting data, praying for money to attend the next clinic, and sharing my heart with all of you!

100 tested, only about 3 million more to go.

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