

Lifestyle change, kidney meds offer hope for mother

BY CHAD HUNTER
Reporter

WATTS – Facing dialysis to fend off kidney failure, Cherokee Nation citizen Shaye Coombes shunned an unhealthy lifestyle for a treatment she hopes could help other Cherokees, including her daughter.

Coombes, 30, and her youngest daughter have polycystic kidney disease, a genetic disorder associated with fluid-filled cysts and the loss of kidney function over time. According to the Mayo Clinic, PKD can cause complications such as high blood pressure and kidney failure.

PKD International states the disorder affects more than 12 million adults and children worldwide. “Over half of those affected will have kidney failure by the time they are 60 years old,” it states. “Many will experience regular pain, disability and anxiety throughout life.”

The first treatment designed to slow the disease – a drug called Jynarque, aka tolvaptan – was approved by the U.S. Food and Drug Administration in 2018, providing hope to Coombes, a licensed nurse now in her second year of taking the medication.

“Our kidneys enlarge. They’re covered in cysts from the inside out,” Coombes said. “What this medicine does is it shrinks them and reduces the number

of cysts so you’re not in as much pain. It puts it kind of like in a remission.”

Coombes remains on the medication because “it’s still working,” she said.

“It’s slowed it down. I should have already been on dialysis a year ago,” she added. “So, it’s doing what it’s supposed to do.”

Unlike other genetic diseases, PKD does not skip a generation, often affecting many people in a family, according to the Polycystic Kidney Disease Foundation.

“My mom has it,” Coombes said. “My grandmother had it. My great-grandmother had it and my youngest daughter has it. It’s really genetic, like each child has a 50% chance of getting it.”

Coombes’ 7-year-old daughter, Cloie, the youngest of three children, is in the disease’s early stages.

“They think she’ll be in her 20s whenever she goes into kidney failure,” Coombes said. “For me, it’s like me being on this medicine is allowing them to work its kinks out, figure out what needs changed here and there. It’s a lot of work and it’s exhausting. But I think one day it could possibly lead to a cure for it.”

Diagnosed at age 10, Coombes said the disease had progressed to the point of kidney failure as she was starting nursing school just before her 27th birthday.

“I hadn’t been taking care of my health,” she said. “When I was a kid, I



Shaye Coombes

went to the doctor because my mom took me. But once I turned 18, I never went back to the doctor and I got really, really sick. I went to the ER, and they told me my kidneys were shutting down.”

At that point, Coombes learned about the medication, but it took her more than a year to get approved.

“There had never been a medicine for our disease ever,” she said. “But they denied me, said I wasn’t a good candidate for it because I was really unhealthy. I had uncontrolled blood pressure. I smoked about a pack and a half of cigarettes a day. I took opioid painkillers every day. I was anorexic. There was just a lot of things I wasn’t taking care of.”

With dialysis as her remaining option, Coombes improved her health in hopes of becoming eligible for the new drug. “They gave me six months, so I quit smoking cold turkey. I quit taking pain pills cold turkey, I gained 20 pounds,” she said. “I come back, and they were like ‘this is a completely new person,’ so they approved me.”

Despite the approval, Coombes hit a financial roadblock. “It costs about \$15,000 to \$30,000 a month to take this medicine,”

she said. “Of course, I couldn’t afford that so they suggested me to a patient assistance fund program, and they told me no for another six months. Then finally they approved it.”

While there are benefits for Coombes, there are risks involved with taking Jynarque, which carries with it a warning for serious and potentially fatal liver injury. According to the drug makers, the most common side effect is thirst and increased fluid intake.

“When I first started taking it, it was really hard on me,” Coombes said. “I was so thirsty I think I drank probably 30 bottles of water a day. It makes you pee and you flush everything out. So it’s basically filtering your kidneys for you.”

In general, she said, “It’s really an amazing medicine, but people don’t know about it.”

“I have multiple family members with this disease that aren’t doing anything to treat it,” Coombes said. “Tons of Cherokee citizens have this disease. My grandmother, there were nine of them and four of her siblings had it. I had an uncle with it who lived on dialysis for 11 years before he passed away. Then I have a cousin that passed away from it a couple of weeks ago and she was 38.”

A notable Cherokee who suffered from PKD was the late Principal Chief Wilma Mankiller.

COURTESY
In a side-by-side photo, Eastern Band of Cherokee Indians citizen Sheyahshe Little-dave displays a 52-pound weight loss since starting an exercise and diet regimen three years ago. The left side is from 2017, during a hike before the “Remember the Removal” Bike Ride. The right side is a photo from this year, sporting the same T-shirt.



Little-dave continues health journey

COVID cases top 600 within CN’s health system

BY CHAD HUNTER
Reporter

TAHLEQUAH – The number of COVID-19 cases within the Cherokee Nation’s health system is nearing 700 following a spike in July.

On July 29, Health Services had 693 verified cases. But on July 20, CN Health Services Executive Director Dr. Stephen Jones told the Tribal Council that as cases climbed statewide to 25,000-plus, the tribe’s health care system had seen more than 500 of its own. Less than two weeks prior, that number was 250.

“So, 506 is a lot of cases, and I’d say that probably half of those have come in the month of July,” Jones said during the July 20 Health Committee meeting. “But it’s pretty low considering the number of people that we serve.”

BY LINDSEY BARK
Reporter

CHEROKEE, N.C. – After coming out of a toxic relationship, learning to raise her two young sons and being at her heaviest weight, Eastern Band of Cherokee Indians citizen Sheyhshie Littledave held nothing back after completing a 950-mile bike ride with other Cherokees on the 2017 “Remember the Removal” Bike Ride, beginning her health journey.

Littledave said the ride saved her life in unexpected ways. “I was at my heaviest weight at 231 pounds. I was struggling with learning how to be a single mother to two young boys and trying to figure out who I was as an individual outside of a very toxic and unhealthy relationship. The moment we reached the Oklahoma line I broke down because it was then that I learned, even at my heaviest, I was a mentally and physically strong person.”

Though it was a struggle and she beat herself up on the ride, not feeling good enough, she said the support system she had helped her through and was part of the motivation she needed to continue with the ride and onto a healthier lifestyle.

“I had to take a very hard look at myself after the ‘RTR’ bike ride,” Littledave said. “What kind of person do I want to be? How do I want my kids to remember their childhood? Do I want them to remember growing up with an angry mother unable to just be comfortable in her own skin? How will that reflect on their own self-worth?”

She said beginning her health journey was not easy as she struggled with various diets and hit plateaus.

In 2018, she was inspired by a mentor at work who had success with a program called BeachBody.

“My problem was that I used food as a coping mechanism, eating made me happy and then it made me feel incredibly miserable,” Littledave said. “I didn’t understand portions and got frustrated when I’d eat a salad one day and didn’t see significant weight loss the next. I wanted instant results to keep me motivated.”

She said she signed up for the BeachBody program, started using Shakeology (a protein supplement shake program), committed to portioned meals and doing 30-minute workouts per day.

“I had a good friend that used her lunch breaks to go on runs with me. I went from barely being able to run consistently for 90 seconds without having to stop and walk to completing a 5k for the first time in my life,” Littledave said.”

At 52 pounds down, she said her clothes fit better now but there are still goals to be achieved and challenges to be faced. “I think the challenge is that once the weight starts coming off, it doesn’t mean the journey is over. You can lose all the weight you want and still look in the mirror and not like what you see. Health journeys are just as much internal as it is external.”

She said those who want to start, they just have to start somewhere whether it’s incorporating a 30-minute walk every other day, cutting out fast foods or drinking more water.

“Today I continue to commit to my daily workouts. I still drink my Shakeology. I pay better attention to my portions, drink more water and really try to listen to my body – am I hungry or am I bored? It’s a process and I’m still learning,” Littledave said.

Within the CN’s boundaries and including Tulsa County, there were approximately 9,000 cases, Jones said. “So, we’re doing pretty well. I feel like we’ve done a very good job getting the message out about wearing a mask and social distancing.”

The CN has administered approximately 10,500 COVID-19 tests. Of those who tested positive, the majority range in age between 18-49.

“Over half of our patients are in that age group,” Jones said. “I think that’s the same trend we’re seeing across the nation and across the state.”

The CN has reported 10 cases in children 4 years old and under, and 47 cases in the 5-17 age bracket as of July 20.

Chief of Staff Todd Enlow said several positive COVID-19 cases are linked to recent school functions in the high school age range. “So, that is a concern we have moving forward, being able to properly social distance and have students wear masks when they’re around one another,” Enlow said.

Since tracking COVID-19, the CN has reported at least five deaths within its health system.

“The state, within our boundaries, has had 115 deaths,” Jones said. “Death is a terrible tragedy, but considering the numbers that were positive in our area and across our state, it looks like we’re doing a good job at catching it and giving people services that they needed.”

Jones estimated that just under half of the tribe’s current hospitalizations are related to COVID-19.

“That’s increased a little bit, but not to the point that we’re very, very concerned,” he said. “We have the capacity to double our inpatients. We haven’t had to go into any of those measures as of yet, but we are tracking that very closely.”



**U.S. ENVIRONMENTAL PROTECTION AGENCY
PUBLIC COMMENT PERIOD FOR THE
NOTICE OF INTENTION TO DELETE THE
TULSA FUEL AND MANUFACTURING SUPERFUND SITE
Collinsville, Tulsa County, Oklahoma
From the National Priorities List
July 2020**



The U.S. Environmental Protection Agency (EPA) announces the opening of the 30-day public comment period associated with EPA’s intent to delete the Tulsa Fuel and Manufacturing Superfund Site from the National Priorities List (NPL), which is Appendix B of the National Oil and Hazardous Substances Pollution Contingency Plan. EPA and Oklahoma Department of Environmental Quality (ODEQ) have determined that all appropriate fund-financed responses under the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA), as amended, have been implemented and completed for the site. This deletion, however, does not preclude further actions under Superfund.

The public is invited to comment on this proposed decision to execute a deletion of this site from the NPL. A 30-day public comment period will begin July 16, 2020, with an official announcement in the Federal Register, and will end August 17, 2020. Written comments must be postmarked no later than the end date of the comment period and should be addressed to:

**Michael Torres, Remedial Project Manager
U.S. Environmental Protection Agency
Superfund Division (SEDRL)
1201 Elm Street, Suite 500
Dallas, Texas 75270-2102**

Comments may also be submitted through the Internet by the end of the public comment period to:

<http://www.regulations.gov>

Questions concerning the site deletion process should be directed to Michael Torres at (214) 665-2108 or 1-800-533-3508 (toll free).

Copies of the documentation the EPA used in proposing this deletion action and the “Direct Notice of Intent for Deletion” are available for public review at:

**Collinsville Public Library
1223 W. Main Street
Collinsville, OK 74021
(918) 549-7528**

For more information about the site and the documents related to the proposed partial deletion, please go to: <https://www.epa.gov/superfund/tulsa-manufacturing>

For press/media inquiries, please call the EPA’s Press Office at (214) 665-2200.

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Contact your local Indian health care provider for more information, visit [Healthcare.gov](https://www.healthcare.gov), or call 1-800-318-2596.