Living the Dream

Health care advocate and aspiring actor Jackie Johnson finds himself in the spotlight after being cured of hepatitis C.

December 3, 2018 By Tim Murphy

Jackie Johnson, 42, has finally begun to live his dream. Not only did he recently start working for Amida Care, a nonprofit Medicaid plan specializing in HIV that also covers his own health care, but he's also pursuing his lifelong goal of being an actor. And after a stint living with a roommate in Brooklyn, he now has his own apartment in the Bronx.

"My first week here, in 2014, I was pinching myself, asking, 'Am I really here?'" he says. "My neighborhood looked just like the Brooklyn you see on TV!"

However, getting cured of hepatitis C has been arguably one of the best things to happen to him since he moved to New York.

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Born in Dallas, Johnson more or less grew up with his cousins after his siblings died young. He caught the acting bug early and was always auditioning for different roles, including a part in the kid version of Michael Jackson's "Bad" video.

"It was always just me and my mom, who worked two or three jobs," he says, so he learned to do the cooking. "Fried chicken, cornbread, spaghetti and Hamburger Helper," he recalls.

They were so financially challenged that they would wait to celebrate Christmas until after his mom got her income tax refund so she could buy presents. Growing up, Johnson would wake up with his mom at 3 a.m. She would go to work, and he would ride a bus to his grandmother's place and go back to sleep there before waking up again to go to school.

After high school, Johnson pursued his bachelor's degree in business and then worked for several years in accounting at Sears and as a manager at Taco Bell. During that time, he tested HIV positive.

Not long after that, he started experiencing extreme fatigue daily. "I thought it was from my HIV meds," he says. But a doctor's visit led to a hep C test—and a positive diagnosis in 2010. Johnson believes he contracted hep C when a friend presumably neglected to use a sterilized needle while

giving him a tattoo.

A doctor at the time told him that a liver screening showed no scarring and that the hep C treatment of the day was both heavy on side effects and suboptimal. “So I put my hep C on a back burner,” he says. “I didn’t smoke, I ate healthy and I didn’t drink at an alarming level.” His fatigue faded away.

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During that time, Johnson was also cooking up plans to move to New York City. He was saving up money, researching health care options in the Big Apple and seeking roommates. “I wanted a better life for myself,” he says, “so I prayed about it, got my signs from God and got on a plane.”

He moved in with a woman he found online who lived in Flatbush and needed a roommate. She showed him around the Brooklyn neighborhood and he instantly loved it. “Once I went into a bodega [a corner store] and someone bought me cookies,” he says. “The friend I was with said, ‘I’m from New York and that’s never happened to me.’ I’m meant to be here.”

He soon landed a job at a Times Square bakery, rented his own Bronx apartment and connected to health care, rental assistance and other services via Housing Works, a longtime HIV services and advocacy agency, and Amida Care.

“I came to New York knowing nobody and with no family, so Housing Works became my family here,” he says. “They connected me to everything I needed here in one day. They even bought me a haircut at the barber across the street. It would have taken me much longer if I’d tried to connect to all those city services myself.”

“[Housing Works] did much more testing on my hep C than anyone had in Dallas,” he says. By that point, the hep C med Harvoni had arrived on the market and was showing great results with few side effects. After three weeks on treatment, his hep C viral load was undetectable.

“It was mind-blowing to hear the doctor say the labs showed nothing,” he recalls. He stayed on the meds another three weeks, suffering no side effects, and has been hep C–free ever since.

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Johnson has also thrown himself into getting out the word that today’s hep C treatment is usually easy to tolerate and highly effective. He was a hep C advocate for the Bronx’s Brightpoint Health.

“Clients there would say, ‘I don’t believe the doctors. How can they say this works?’ And I would say, ‘Believe me, because I’ve been there.’”

Now, as a member-services staffer at Amida Care, he has even more opportunities to share his personal story with others facing similar challenges. At Amida, he organizes healthy cooking, fitness and art classes as well as two big annual parties for the health plan’s 7,000 members in all

five boroughs.

“I’m so excited!” he says. “I wanted to work [at Amida Care] as soon as they started covering me, but I first needed to get to know New York better.”

“Jackie’s a perfect fit for us,” says Amida Care spokesperson Shakira Croce. “He speaks so wonderfully about his experience, and it’s powerful when people who might have had similar experiences hear his story. It can help empower them to take control of their own health.”

Johnson loves the life he has built for himself in New York since moving from Texas. “I don’t take anything for granted today,” he says. “I work hard and enjoy the simple things. I’m excited all the time!”

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