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Art-ivist Romano Johnson Reaches Out to HIV+ Youth About Amida Care

by Winnie McCroy
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As a child living in the Bahamas, Romano Johnson watched "Showtime at the Apollo" and vowed to his mother that one day, he would perform on that same stage. When he moved to New Jersey in 1996 to finish high school, he set out to achieve that goal, taking the bus and train into the city. But August 2000, he had performed on the venerable Harlem stage.

"When I saw the opportunity, I went for it," Johnson told EDGE. "I always loved New York City -- the atmosphere, the people, the place it provided artists to be among other singers, actors, and models. There is just so much talent here."

Before long, Johnson had finished school and relocated to East New York. Unfortunately, by 2008, he had also discovered that he was HIV-positive. His primary care doctor at Housing Works recommended he access additional services offered by Amida Care, then called Vida Care. Although he had received their monthly invitations to join fitness classes, to make meals or join in meditation, Johnson never really took advantage of them.

That all changed one evening, when his case manager Dana passed him in the hallway as she was entering an Amida Care meeting. She urged Johnson to sit in on the meeting, and as he puts it, "that kind of changed everything."

"I met Stephanie and Roberto, and learned about everything the group had to offer," said 31-year-old Johnson. "Before long, and to my surprise, the members voted for me to become their representative on the board, and I have since been reelected four times."

Becoming involved with Amida Care's many programs forced Johnson to look at his health care in a different way. Before, it was all about the numbers, and who was paying for his medications. Now, Johnson said, he is part of something he can be proud of.

"It changed how I think about my health," said Johnson. "I make sure now that I am working to empower others with HIV, and Amida Care offers so much to help keep you on track. There's a big gap in services between 20-somethings and 40-somethings living with HIV, and there were really no representatives from my generation on that board. But since I have had a social worker and therapist connect with me and empower me, I want to empower others."

In the eight years since Johnson learned of his status, he has worked tirelessly to connect with people of his generation and let them know that he understands their stories, serving as a board member, a Youth Advisor, and recently, becoming a youth representative for ACT Up.

Johnson balances all of this with his work as a musician and recording artist. Calling himself an "art-ivist," Johnson is currently preparing to present a show at the end of the month, and recently performed at a private dinner for some Amida Care members -- a perfect melding of his activism and art.

"I hold these positions because I have a passion for it, and because I am providing a voice for a lot of young people who may not have the ability to step forward," said Johnson. "It's not just about my own health anymore, it's about helping everyone."



(Source:Amida Care)

To that end, Johnson works as an outreach advocate, going into other communities and letting young people know the wide range of services that Amida Care offers. In addition to the basic healthcare services of providing Medicare Advantage Prescription Drug services, advocacy, case management and medical services, they also offer a Live Your Life wellness program of free events through the five boroughs of New York City, where Amida Care members can learn about ways to be healthy physically, mentally, and spiritually. In addition to Latin and African dance classes for fun and fitness, they offer workshops on healthy cooking, art therapy, yoga, meditation, aromatherapy and much more.

"Amida Care's Live Your Life program grew out of direct member feedback that health care needs to be about more than visiting the doctor and taking pills. These events are

designed to meet the social, physical, and emotional needs of our members and build life skills. We thank Council Member Torres for his support in bringing this program to the Bronx community," said Doug Wirth, President and CEO of Amida Care.

Amida Care's Special Needs Health Plan provides comprehensive health coverage and coordinated care to people living with multiple chronic conditions, including HIV/AIDS and behavioral health disorders. The plan is also available to Medicaid members who are homeless, regardless of HIV status. The plan offers a wide network of primary care physicians (PCPs) and specialists, as well as close oversight by an integrated care team to ensure that each individual receives the services and personal attention they need to get and stay healthy.



(Source:Amida Care)

As Johnson said, "Anyone who is HIV-positive can be a member. It's open to anyone in society, even if you are homeless and on Medicaid, even if you are HIV-negative."

As much as he is impressed by their services, what truly touched Johnson's heart is the 'care' that Amida Care staffers share with their clients.

"You can tell when you meet the staff that they really care what's going on with the members," he said. "They don't ever turn off their care. They make sure they are up to members' standards, and in compliance. As a board member, they inspire me to go out into community and get into other organizations. One day I will have to give this seat up, but my fight won't stop there. I will still be active in the community, fighting for change."

But it's not just general altruism that sparks Johnson to continue being a visible presence at Amida Care. When he was younger he struggled with coming out and being visible about his status, daunted by the fact that people in his community derided those who were HIV-positive. He had a therapist and a doctor, but felt very alone because he didn't tell those closest to him what he was struggling with. Rather than share his

serostatus, he moved away from everyone he knew to start a new life.

"What changed everything for me was about three and a half years ago, a close friend called me to tell me that he had HIV," said Johnson. "Instantly, my heart broke. I had been dealing with this for two years prior to him telling me, and I felt that I failed him somehow. I told him that it was okay, that I was going through the same situation. We told our other friend, and he said that he was also HIV-positive and hadn't told anyone."

"This whole time, I was trying to keep something about me away from them, when if I told them at the time, maybe they would have realized that we're not invincible," said Johnson. "I have since made it my business to be open about this. People can say what they want, but as a person that is going through this, I have to be the change. I have to tell people that if you're not HIV-positive, you don't have to be. And if you are HIV-positive, you can take care of yourself and access a complete health care plan, top to bottom. Maybe if I was more of a fighter then, I could have saved my best friends."

Now, it is Johnson's personal mission to educate other young people about HIV. To that end, he is training for public speaking, and encouraging other people, especially those in his generation, to fill in the gap and be present in the fight. He also strives to reach out more to the transgender community, saying, "we need to target these people so they know they are not invisible. They may not have the courage to come to an event where they don't know the people, and that's why we need to reach out with a more hands-on approach."

Working with his mentor Stephanie, Johnson is trying to move on to the next level of public speaking and public service, saying, "This is everyone's fight. A lot of times we look at adults to fix it, but young adults have to be better and stronger, and come up with great new ideas. We could all be doing a lot more."

For information about Amida Care, visit <http://www.amidacareny.org/>



Winnie McCroy is the Women on the EDGE Editor, HIV/Health Editor, and Assistant Entertainment Editor for EDGE Media Network, handling all women's news, HIV health stories and theater reviews throughout the U.S. She has contributed to other publications, including The Village Voice, Gay City News, Chelsea Now and The Advocate, and lives in Brooklyn, New York.



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